DOCTOR OF PHILOSOPHY

Phantom dispositions & devalued bodies

a Bourdieusian analysis of the experiences and perceptions of stroke survivors living in the community

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Siân Mary Russell

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DECLARATION

I, Siân Mary Russell, hereby certify that I am the author of this thesis. Unless otherwise stated, all references cited have been consulted by me; the work presented within this thesis has been conducted by me, and has not been previously accepted for a higher degree.

Signed ……

ABSTRACT

This study was undertaken to explore the experiences of long-term stroke survivors living in the community. This exploration has been informed by Bourdieusian thinking in order to account for the socially shaped embodied subject. A theoretically driven thematic analysis followed by an instrumental case study offered the opportunity to investigate the long-lasting impact of stroke acquired impairments as well as explore and expand upon Bourdieusian thinking tools.

A stroke is a disruptive event which can result in physical and cognitive impairments. It can represent a rupture in the learned dispositions of the habitus. Here dispositions are not changed due to pedagogic effort. Rather, dispositions become threatened and altered by a sudden and catastrophic transformation within the body. Acquired impairments represent a disconnect between the body and the learned dispositions of the habitus exposing the complex relationship between the body, habitus and dispositions and the vital, yet vulnerable role the body plays within it.

This study found that acquired impairments could have a nuanced impact upon an individual's ability to manoeuvre within socio-spatial fields and to negotiate their social capital. This exploration exposed the fundamental role emotions play in the embodiment of social capital and revealed the possibility for stroke survivors to develop a 'devalued identity' due to the changes and challenges they live with in light of their stroke.

Finally this study offers a new tool for the Bourdieusian toolkit: ‘phantom dispositions’. For those who experience a phantom limb, the limb is still subjectively felt yet has no existence in reality and therefore cannot function in reality. This lost limb has formed part of the individual’s history; knowledge of using the limb and ultimately what it meant to have the limb remains despite the individual’s inability to use it in reality. Similarly knowledge and awareness of dispositions remains within a stroke survivor’s habitus yet these dispositions cannot be actualised in practice. The body ultimately denies the habitus the opportunity to actualise itself because certain dispositions are there but not there: phantasms both embodied and disembodied.

THESIS AIMS & OUTLINE

Aims

The key aims of this thesis were twofold. The first aim was to explore the experiences and perceptions of long-term, community dwelling stroke survivors. The second aim was to explore the process of embodiment within the context of stroke acquired disability by engaging creatively with Bourdieusian thinking. This second aim offered the opportunity to theorise with, but also beyond, Bourdieu.

Stroke is a medical emergency which can lead to long term physical and cognitive impairments, as well as psychological and social consequences for around one-third of stroke survivors (Wolfe, Crichton, Heuschmann, *et al.,* 2011). Despite the potentially devastating impact of stroke on the lives of both the stroke survivor and their close friends and family, the long term impact of stroke is given relatively little attention when compared with prevention and acute care (Thompson & Ryan, 2009; McKevitt *et al.,* 2011). However, the longer term needs of needs of stroke survivors have begun to be more readily explored. For example, a recent study by the charitable body, *The Stroke Association* involving 2,200 stroke survivors and carers across England, Wales, Northern Ireland and Scotland explored the needs of stroke survivors living in the community. The report, *Struggling to Recover* (2012), has highlighted that long-term needs are still regularly unmet with stroke survivors often lacking appropriate information provision, health assessment and social support. Long-term stroke survivors can therefore often feel abandoned. This report underlines the need for improvements in support for stroke survivors living in the community in the long-term.

Such conclusions highlight that further research is required to understand the personal experience of stroke in the long-term context and to gather data to help inform policy.

Within this thesis stroke has been viewed through the lens of disability and illness. Research into disabilities has become increasingly concerned with the process of embodiment (Turner, 1996; Edwards & Imrie, 2003; Thibodaux, 2005; Loja *et al.,* 2013). The concept of embodiment represents an appreciation of the body as both corporeal and interwoven with society: "*[t]he body is in the social world but the social world is also in the body*" (Bourdieu 1990a: 190). For some, stroke represents a temporary disruption of the body from which they recover, while for others it can lead to a varying array of physical and cognitive impairments and disabilities. As such, stroke was deemed a potentially fruitful condition through which to explore embodiment and visa-versa. In order to conduct this exploration the theoretical toolkit of the deceased French sociologist and anthropologist Pierre Bourdieu was utilised. The body and the interlocked nature of structure and agency play a key role within Bourdieusian sociology which made it a profitable approach to use in exploring the experiences and perceptions of stroke survivors. Furthermore, such an endeavour provided the opportunity to explore and expand upon Bourdieu's key thinking tools.

Outline

This thesis begins by introducing the topic of stroke as a cause of disability and chronic illness. As embodiment concerns the interwoven nature of the body and the social world it occupies, the social and cultural representations of disability are given some

consideration. It will be argued that the social and cultural milieu[1] is structured upon a ubiquitous and insidious ableist doxa in which disabled bodies are typically defined within the confines of narrow stereotypes, or excluded and shunned. The consequences of stroke and the grand narrative of disruption which defines stroke within the literature are then outlined before the theoretical toolbox offered by Bourdieu's conceptual and relational thinking tools is introduced.

The second chapter provides a comprehensive outline of Bourdieusian concepts. Bourdieu's thinking tools are not to be conceptualised solely as a series of interrelated ideas but also as a method: a *way of thinking*. The key concepts of habitus, capital and field are outlined alongside less commonly used concepts such as conatus and illusio. Much of the literature in which Bourdieu's ideas are utilised for analysis focus only on habitus, capital and field and often on Bourdieu's early conceptualisations. This can lead to a shallow reading and application of Bourdieusian concepts. As such this second chapter aims to widen the scope of thought beyond Bourdieu's well known triad of habitus, capital and field.

The notion to utilise Bourdieu's theoretical toolkit in order to explore embodiment within the context of stroke was made at the outset of this study due to its clear potential. However, early reading of the stroke literature revealed that Bourdieu, and Bourdieusian analysis, had apparently either not been widely used or not used at all within stroke research. In order to gauge whether the use of Bourdieusian thinking

[1] The focus here is on Western societies

within this study would have any claim to originality a systematic review was undertaken. This review is presented in Chapter Three. The review found no evidence that Bourdieu has been used specifically within research focusing on stroke survivors and as such this study does appear have a claim to this novelty.

The fourth chapter within this thesis provides a discussion of the ontological and epistemological considerations which informed the methods chosen. Both a survey tool (typically aligned with quantitative approaches) and semi-structured interviews (typically used within qualitative research) were undertaken. Therefore, this study utilised mixed methods in order to collect data; however it should be noted that the data was ultimately analysed qualitatively. Due to the controversies and debates surrounding the use of both quantitative and qualitative methods within a single study, the reasoning behind the approach used needed to be outlined. As such this chapter provides some critique and discussion regarding the arbitrary dualisms between qualitative and quantitative approaches and some discussion of 'mixing methods'. Justification for utilising theory explicitly as an approach to data collection and analysis was also warranted. As such the fourth chapter also highlights the author's *sympathies* with both the critical realist perspective and with the underlying principles of adaptive theory. The adaptive theory approach was not explicitly followed within this study but its underlying principles of using empirical data to explore theory, and vice versa, in an iterative process represented a guiding principle within the approach to data analysis.

The fifth chapter of this thesis outlines the use of methods in practice. In order to access research participants a survey tool was utilised. This tool generated a sampling pool and provided background data on each interviewee. The survey data enabled personalised probes to be created within each individual interview guide and *assisted* in the analysis of interview data. Despite the use of a survey tool, within this study the main forms of analysis were qualitative: a theoretically driven thematic analysis followed by an instrumental case study. The theoretically driven thematic analysis was an iterative process driven by both theory and empirical data. After a data familiarisation phase and a scoping theoretically driven thematic analysis phase, specific themes were then focused on in detail. A focused thematic analysis driven by a data concerning how the stroke survivors both manoeuvred within socio-spatial fields and negotiated their social capital was undertaken. Other theoretically stimulating themes were developed and mined via an instrumental case study. These two key themes were 'phantom dispositions' and the embodiment of a 'devalued identity'. The role of the instrumental case study was to enable theoretical exploration. As such the cases utilised played a supportive role in the development of theoretical ideas.

The findings from the thematic analysis and instrumental case study are presented in chapters Six and Seven respectively. The role of emotion in embodiment was a strong theme within the thematic analysis. Within Bourdieusian theory the role of emotion is not explicitly considered. However the iterative process utilised within analysis provided the opportunity to explore this and ultimately exposed the subtle yet crucial role played by emotions within Bourdieu's work and the nuanced role emotion plays in the embodiment of the social in the body as individuals manoeuvre within socio-

spatial fields and negotiate their social capital. By mining Bourdieusian theory alongside the empirical data it became clear that emotions do play a crucial role, particularly in dominating and restricting bodies in acts of symbolic violence and ultimately the in perpetuation of inequalities. These findings are presented and discussed in Chapter 6. Within Chapter 7 a novel adaptation of Bourdieu's concept of dispositions is presented and discussed. According to Bourdieu the habitus is a durable system of dispositions developed over time and thus containing its own history. Dispositions enable a feel for the game and a sense of ease with one's body. The bodily hexis, '*political mythology realised, embodied, turned into a permanent disposition, a durable way of standing, speaking, walking, and thereby thinking and feeling'* (Bourdieu 1977: 94), reveals the deepest dispositions of the habitus. In other words the bodily hexis is the objectification of habitus through the taken for granted manners and dispositions of the body. Acquired impairments can disconnect the habitus from the bodily hexis and thus deny the habitus the right to actualise itself in practice. It will be argued that these lost capabilities create 'phantom dispositions'. The habitus is historical and thus the memory of bodily capabilities and dispositions remain within a body which can no longer objectify them. These dispositions still form part of the habitus as an enduring memory of able-bodiedness but can no longer be realised in practice. The issue of impaired bodies lacking value and legitimacy was the most prominent underlying theme, appearing with varying degrees of subtlety throughout the analysis. This has been conceptualised as 'devalued identities' and 'devalued bodies'. Both phantom dispositions and the process of shifting from able-bodied/normal to disabled/abnormal both play a role in problematising the habitus and lodging it in a somewhat liminal state. This is due to the historical nature of the habitus the memory of able-bodiedness and thus both the practical mastery of the

body and symbolic value associated with it, lingers within the disabled body causing a long lasting sense of loss and frustration. Reconciling the former self with the current self thus becomes challenging and the habitus becomes betwixt and between two worlds of the able-bodied and disabled where the latter world represents loss, exclusion and limits.

The final chapter within this thesis provides a succinct summary of the conclusions drawn from the findings and reflects upon the implications these have for practice before considering the limitations of the study and presenting possible avenues for further research. The findings of this thesis expose a genuine need to improve long-term care for stroke survivors and their families, particularly making clinical psychologists more readily available and providing stroke survivors, and their carers, with mechanisms to cope with the long-term consequences of stroke. Other key implications are increasing the training and understanding of employers regarding both visible and 'invisible' impairments and investing in imaginative ways to enable stroke survivors whose impairments may have detached them from former hobbies and activities to become engaged with old and new activities. Such activities can provide an opportunity to perpetuate and augment the self and thus combat the frustrations associated with impairment and disability. Ultimately the findings suggest that for community dwelling long-term stroke survivors reconciling the pre-stroke, able bodied self with the current post-stroke, disabled or impaired self can represent a struggle. However, for many this struggle is not necessarily observable as such struggles are often based in bodily emotions and are thus often not explicit. Additionally the theoretical approach utilised provided an insightful and creative lens

through which to explore the processes of embodiment. A Bourdieusian analysis particularly exposed the manners in which the body can become out of sync with the historical sense of self and also the subtle yet extremely powerful role of emotion within social interaction and how this can deeply impact upon an individual's sense of legitimacy and value in regard to the people and the fields they interact with.

CHAPTER 1: SETTING THE SCENE: STROKE AS A CHRONIC ILLNESS & DISABILITY

1.1: INTRODUCTION

The purpose of this thesis was to explore the experiences of long-term stroke survivors living in the community. This exploration has been informed by Bourdieusian thinking in both approach and analysis in order to account for the socially shaped embodied subject. The objective of this chapter is to introduce the core topics of concern to this thesis; stroke as a chronic illness and disability, embodiment and the 'theoretical toolkit' offered by the substantial body of work produced by sociologist and anthropologist, Pierre Bourdieu.

Research regarding the experience of living with chronic illness and disability is considerable and growing. In broad terms this research has explored either external influences which impact upon behaviour or the subjective internal experiences of illness as opposed to fully realising and accounting for the process of embodiment (Edwards & Imrie, 2003; Turner, 1996). The body is a fundamental component of individual agency, a significant focus of anxiety and concern in regard to personal identity, and yet also an everyday and mundane object; we are all aware of '*what it is to have or to be a body*' (Turner, 1991: 22). The concept of embodiment, as Gordon explains, refers to:

> *"…the bodily aspects of human subjectivity, the biological and physical presence of our body as a necessary precondition for the experience of emotion, language, thought, and social interaction. It is our kinesthetic awareness of the body as the vehicle through which we experience the*

> *sensorimotor, perceptual, and nonconceptual lived world. This is not a cognitive understanding of self in the world, but a proprioceptive, nonconceptual awareness … that is tactic, prereflective and intersubjective" (2013: 122)*

As such studies of embodiment are not so much about the body as they are about the cultural and social experience of bodies in context or of '*bodily being-in-the-world*' (Csordas, 1999: 143). Becoming disabled or developing a chronic illness can fragment an individual's historical sense of self as well as their sense of place within social space; the relationship between body, self and society can become problematised. In the succeeding passages of this chapter what constitutes chronic illness, disability and stroke will be outlined before the importance of embodiment is given consideration and Bourdieu's 'theoretical toolkit' is introduced. The main concern of this chapter is to discuss disability, chronic illness and stroke. The key concepts utilised by Bourdieu are given a detailed discussion in the following chapter.

1.2: CHRONIC ILLNESS, DISABILITY & STROKE

Within the United Kingdom (UK) disability has been defined within the Equality Act 2010 as a '*physical or mental impairment which has a substantial and long-term adverse effect on the ability to carry out normal day to day activities*' (Lockwood, Henderson, & Thornicroft, 2012: 182). According to the World Health Organization (WHO) chronic conditions or illnesses are defined as requiring '*ongoing management over a period of years or decades*' (WHO, 2005). Disability and chronic illness have distinctions yet considerable convergences. Illnesses such as cancer or human

immunodeficiency virus (HIV) and illness events such as stroke can lead to both chronic illness and disability. Yet disability has other causes; for example a vehicle collision resulting in brain or spinal cord injury which can lead to long-term, chronic health issues. Chronic illnesses themselves are often not static in that the experience of the condition can be changeable; there are '*good days and bad days'* (Charmaz, 1991: 9). In this sense such illnesses are disabling as they can disrupt social activities such as working, or performing normal daily tasks in a manner that is not wholly predictable. In contrast some disabilities are relatively static in terms of the on-going experience and *could* be considered 'healthy disabilities' and those who experience such disabilities as 'healthy disabled'*; 'people whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future'* (Wendell, 2001). Defining chronic illness and disability is therefore not a straightforward endeavour. Understanding chronic illness and disability present further challenges and has been subject to considerable debate and contention within the social, psychological and political sciences for decades. These debates rest within the heart of this thesis. However, a fully comprehensive review and critique of the considerable body of literature associated with both disability and chronic illness is not the concern of this chapter. It is more pertinent to review the broad brushstrokes within these debates before introducing and discussing stroke and Bourdieu's theoretical toolkit.

1.2.1: Health, Illness & Disability

Historically health has been defined as the absence of disruption and the maintenance of 'normalcy' while illness has been characterised in a narrative of abnormalcy; for

example, Talcott Parsons' well known analysis in which illness is posited as social deviance. According to Parsons an illness is:

> "*… a state of disturbance in the "normal" functioning of the total human individual, including both the state of the organism as a biological system and of his personal and social adjustments*" (2005 [1951]: 431)

Within the Parsonian model the ill are morally required and expected to pursue recovery in order to effectively fulfil social roles. Simmering within this analysis of health and illness is the biomedical model of illness and disability. The biomedical model frames the difficulties faced by disabled individuals as a problem centred in the individual's body and reduces the identities of the ill and disabled to one characterised by deviance (Zitzelsberger, 2004; Edwards & Imrie, 2003). Parsonian analysis has been subject to considerable criticism and reconsideration to the point where it could be viewed as a '*relic of the dim and distant past'* (Williams, 2005: 123). However, the biomedical model, or medical gaze (Foucault, 1995 [1977]), remains pervasive within lay and official conceptualisations of health and illness. For instance, the WHO views the eradication of disease as their overarching aim. This exposes an omnipresent cultural view that illness, chronic illness and disability are a problem, are threatening and ultimately something to fear. Such attitudes are problematic as the individual disabled or ill body becomes a site of negative symbolic value.

The social model of disability presents a direct challenge to the biomedical model of disability. Within the social model disability equals external social oppression, be it in the form of architectural spaces which exclude by design or social attitudes, rather than the bodily impairment itself. This model has had a profound, and or the most part positive, impact on laws surrounding the treatment of, and social inclusion of, disabled people (Shakespeare & Watson, 2001). However this model has faced criticism for not effectively accounting for corporeal, embodied identity: the body ultimately remains unchallenged and neglected within this model (Shilling, 2003). As Elizabeth Wilson argues '*how can a critical habit nurtured on antibiologism produce anything but the most cursory and negating critique of biology*?' (Wilson, 1998: 16). Furthermore, the social model of disability is at risk of refusing disabled people the right to their own feelings and emotions about their own disablement (Morris, 1991): mourning the lack or loss of physical or cognitive ability within the disabled individual appears illegitimate if the social model is considered too strictly. Therefore, neither the biomedical nor social model of disability adequately captures the lived experience of disability. Disability is neither simply biological nor social; disability is about *'barriers to "doing" as well as barriers to "being"'* (Thomas, 1999: 3). Neither of these models successfully account for the '*socially shaped embodied subject'* (Shilling, 2004: 474). This reflects a Cartesian dualism which has had a ubiquitous historical influence on approaches towards the body within the Western philosophical and sociological accounts of the body where the body is a mere material vessel for the spiritual, abstract mind. Recent years, however, have seen a shift in approach to illness, disability and the body which seeks to account for embodiment and, indeed, disembodiment (Turner, 1996; Shilling, 2003).

1.2.2: Ableism & the Cultural Milieu: The 'Socially Shaped Embodied Subject'

Bodily impairments represent '*an organic, literally embodied fact'* (King, 1993: 72). Therefore disabled individuals will *experience* their bodies and the world they inhabit in a manner which differs from bodies which are absent of impairments, impacting upon their embodied identity and their own bodily competencies. Yet beyond the individual body, disability and impairment are often highly visible (e.g. a wheelchair) or remain invisible until a context arises in which an impairment or disability is exposed (e.g. anxiety disorder / chronic fatigue syndrome). Their visibility ultimately makes disabled and impaired bodies sights which are subject to considerable assumptions and beliefs based on their symbolic value. Of great importance to the embodiment process, therefore, are the symbolic representations of disability within the cultural milieu in which people with disabilities are '*othered*'.

Disabled and ill bodies, and their associated identities, are the focus of much categorisation and stereotyping. Representations of disability within Western cultures are characteristically *ableist.* Campbell defines ableism as:

> *"… a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human"* (2009: 5).

Typical symbolic representations of disability are captured by Kriegel's (1987) analysis of the representation of disabled people in literature. Kriegel concludes that people

with disabilities are typically placed into narrow categories of the *demonic cripple* who is angry at the world due to his disability; the *charity cripple* who is pitied, seeks love and affection and draws out those feelings in others; the *survivor cripple* who has carried on bravely despite the presence of disability and is thus viewed as inspirational and finally the *realistic cripple* who does not resent, seek pity nor inspire but simply lives with disability as a fact of his or her existence (Bryan, 2010; Shakespeare, 1994). According to Kriegel:

> *"[t]he world of the crippled and disabled is strange and dark, and it is held up to judgement by those who live in fear of it. The cripple is the creature who has been deprived of his ability to create a self … He is the other, if for no other reason than that only by being the other will he be allowed to presume upon the society of the "normals". He must accept definition from outside the boundaries of his own existence"* (Kreigel, 1987: 33 [cited in Shakespeare, 1994]).

At the heart of Kriegel's analysis is that disabled people are typically given a presumed identity by others as opposed to being given the opportunity to express and create their own identity, which is not engulfed by disability alone. These categories have been expressed under new labels elsewhere; for example, in critiques of film and television dramas such as Norden's (1994) term the 'evil avenger', which parallels the demonic cripple, used to highlight the use of disabled, impaired, or disfigured individuals as the 'bad guys' within popular film (Harnett, 2000). The survivor cripple is

paralleled by the notion of the 'supercrip' where a disabled character's worth is often measured against their willingness to strive to overcome their impairment, that is, to be as 'normal' as the non-impaired characters that typically surround them (Darke, 1998; Harnett, 2000). It is also worth stressing that when disabled people do appear within the literature, television, or film it is often, precisely *because* they are disabled – their disability is a central part of the story arc or used to bolster the caring or heroic nature of a non-disabled central character - as opposed to any other facet of their existence. Within film, as in literature, a character with a disability is engulfed by their disability: it is all of, or at least the key aspect of, their character and purpose of their character (Darke, 1998; Harnett, 2000). Darke argues that these '*normality dramas'* are typically viewed by predominately non-impaired audiences whose perception of the screen drama is:

> "… *rooted in the socially hegemonic interpretation of impairment as a medical and 'individual' problem to be overcome or eradicated … along with belief in normality"* (1998: 190).

Disabled and ill bodies are therefore either absent within literature and film or present because of impairments. Disabled and ill bodies are thus othered as the 'abnormal' against able-bodied 'normality'. Print media also typically presents problematic portrayals of disability. A recent content analysis and 'audience perception study' conducted by Briant, Watson and Philo (2012) found that the global financial crisis, resulting recession and benefit cuts has seen a negative change in the representation

of disability within UK based newspapers. Articles from 2004/5 were compared within those from 2010/11 exposing a drop in sympathetic articles or those caricaturing successful disabled people within the 'supercrip' stereotype towards articles where disabilities were viewed with suspicion and those with disabilities characterised as 'scroungers', 'fraudsters' and 'work-shy'. The authors conclude that disabled individuals, as a group, have:

> "*…become, for some newspapers, a folk devil and this change has been justified by a need to reduce costs in welfare provision as a response to the global financial crises*" (Briant, Watson & Philo, 2012: 874).

The media coverage of the Paralympics however sits in stark contrast to the folk devil discussed by Briant, Watson and Philo. At the heart of the Paralympic media coverage is a problematic notion of 'heroism' which is far removed from the day-to-day experience of disabled people (Bush *et al.,* 2013). A subtle undertone within the representation of Paralympians and the Paralympics is the assumption that Paralympians deserve attention and adoration because what they are doing is deemed to be remarkable. This leaves other disabled people at a greater disadvantage. This is potentially typified by the coverage of the 2012 Paralympics where the Paralympians were characterised as 'superhumans' (Bush *et al.,* 2013). The term 'superhuman' is, in a sense, a positive step forward as the Paralympian's humanity is acknowledged within the term, however it holds undertones of the 'supercrip' stereotype renowned within Paralympic sport (Howe, 2011; Black & Pretes, 2007) and presents:

> "*… false perceptions of empowerment in the sense that the Paralympics remains in the hands of non-disabled people who save and empower helpless disabled people*" (Braye, Dixon & Gibbons, 2012: 4).

Howe (2011) argues that the technology used by certain Paralympians has the potential to 'normalise' their bodies and produce 'sporting cyborgs'. While the representations of these 'cyborgs' does further the media coverage of disabled bodies, presenting them within a positive light, they also let ableism in through the back door:

> *"[w]ell-known, successful disabled people are put on a pedestal for their demonstrated ability to triumph. This triumph is used to validate the disabled individual and to alter societal perceptions. Consequently, the wish to see disabled people who 'have done it' is particularly intense while the pitiful disabled trigger antipathy because they reproduce and reinforce disabled people's inferior positionality and exclusion*" (Kama, 2005: 447).

Thus literature, film, television and print media representations of disability are often dehumanising and caricatured. Representations are also often polarised representing people with disabilities as either pity worthy, something to fear and revile - as encapsulated within Shakespeare's (1994) discussion of disabled people as 'dustbins for disavowal' - or as triumphant 'supercrips'. This perpetuates the othering process in

that disability remains the distinguishing feature of their representation and reaffirms ableist conceptualisations of disability.

Outwith media, literature and film the process of othering disabled people is furthered by purposeful segregation within physical and social space as Kitchin argues '*spaces are currently organised to keep disabled people `in their place''* and *'spaces are social texts that convey to disabled people that they are `out of place*' (1998: 344). It can be argued, therefore, that society (semi)consciously questions the legitimacy, capability, *value* and competence of disabled bodies. As Paterson and Hughes state:

> "...*the information that animates the world is dominated by non-disabled bodies, by a specific hegemonic form of carnality which excludes as it constructs"* (1999: 604 [cited in Edwards & Imrie 2003]).

As such negative views of being disabled also form a 'personal tragedy' model of disability: *better dead than disabled... [t]he erroneous idea that disabled people cannot be happy, or enjoy an adequate quality of life* (Swain & French, 2000: 473). This makes the 'threat' of disablement as something to fear. Ynestra King states:

> *"… of all the ways of becoming "other" in our society, disability is the only one that can happen to anyone, in an instant, transforming that person's life and identity forever"* (1993: 74).

Those who have acquired their impairments '*in an instant'* as opposed to being born with an impairment are faced with maintaining a sense of who they *are* in a world where their body has suddenly become a symbol of otherness; of the illegitimate or 'invalid' (Hughes, 2000). The key matter here is that such individuals have previously existed within a world where they were the able-bodied while those with disabilities were the 'other'. As Merleau-Ponty states:

> *"…the enigma is that my body simultaneously sees and is seen. That which looks at all things can also look at itself and recognize, in what it sees, the "other side" of its power of looking… my body is a thing among things; it is caught in the fabric of the world"* (1993 [1964]: 124).

Those who have disability thrust upon them now exist in a world where they are disabled and are (semi)consciously aware of the negative connotations associated with their altered body. As identities are socially and spatially embedded, this awareness presents a fundamental threat to sense of self in social space. To become disabled, as Galvin notes:

> "*…is to be relegated to a marginalised status in society and brings into high relief for the disabled person the advantages accorded [to] those who inhabit the unacknowledged "centre""* (2003: 149).

Acquiring an impairment or disability restricts access to these advantages and privileges, and can see the individual come to be defined in very different ways. Stroke, a central concern of this thesis, is a medical emergency; however, beyond the acute phase stroke is ultimately a sudden event which can lead to impairment and disablement. This makes stroke a particularly intriguing condition to explore through the lens of embodiment.

1.2.3: Stroke: A Chronic Illness & a Disability

According to the WHO stroke is defined as:

> "*… rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer, or leading to death, with no apparent cause other than of vascular origin*" (Wolfe, 2000: 276).

However, for those who experience a stroke, and survive, it equates to much more. Stroke is an attack on the brain, an organ responsible not just for the functions of the body but also memories and emotions. Our brains contain who we are:

> "*[t]he brain, the seat and soul of our fears, our joys, our achievements, our relationships, our creativity, our happiness, our sadness, our identity, our memory, our history*" (LaPointe, 2011).

Stroke is therefore a direct threat to functional ability and to the fundamental bedrock of a person. It is estimated that there are 30 million living stroke survivors globally and within the UK recent estimates suggest that stroke is the third main cause of death and the main cause of adult disability (Fletcher-Smith *et al.,* 2013). As the majority of stroke survivors are left with impairments, and thus disabilities, due to their stroke the condition represents '*a leading cause of adult disability worldwide and a major contributor to the global burden of disease'* (Fletcher-Smith *et al.,* 2013: 6). The potential impairments caused by a stroke are wide ranging and complex and the personal and social impact considerable.

Stroke Acquired Impairments

The potential physiological impairments that can be caused by stroke are kaleidoscopic and multifaceted. Stroke can also lead to remaining on medication for life. As such stroke straddles the line between chronic illness and disability. Depending of severity of stroke, and area of the brain that is damaged, stroke can result in lasting disabilities and impairments as diverse as bladder or bowel incontinence, weakness (hemiparesis) or paralysis (hemiplegia) including within the throat (dysphagia) and problems with co-ordination balance as well as difficulties with posture and gait (ataxia). Unsurprisingly, physical aids such as walking aids and wheelchairs are often required following stroke. Stroke survivors can also be left with cognitive impairments. As Cumming *et al.* state cognition is:

> *'…not a unitary concept; it incorporates multiple domains, including attention (focusing, shifting, dividing, or sustaining attention on a particular stimulus or task), executive function (planning, organizing*

> *thoughts, inhibition, control), visuospatial ability (visual search, drawing, construction), memory (recall and recognition of visual and verbal information), and language (expressive and receptive)'* (2013: 38).

The cognitive impairments experienced by stroke survivors are therefore varied and include visual disturbance, communication problems such as aphasia, which occurs in approximately one third of stroke survivors (Brady *et al*., 2012). Aphasia (sometimes called dysphasia) refers to the impairment of the language system following brain damage. Aphasia is cognitively based and differs from speech problems caused by dysarthria which are caused by muscular weakness. The impairments associated with aphasia differ depending on the damage and location of the damage within the brain but can involve the impairment of expression and comprehension of speech, reading, writing, understanding symbols and gesture (Brady *et al.,* 2012). Stroke survivors can also experience difficulty filtering out ambient noise, loss of emotional control, problems with concentration, memory and learning as well as fatigue, dementia and epilepsy, and other associated healthcare problems such as falls (Fletcher-Smith *et al.,* 2013). As such stroke survivors will often experience difficulties maintaining activities of daily living (ADL) making it difficult to resume their pre-stroke lifestyle. Recent estimates suggest that approximately half of stroke survivors will become dependent on the assistance and support of others for day-to-day living (Fletcher-Smith *et al.,* 2013). Thus the main personal and social burden of stroke is adjusting to, and living with, disability and impairments.

The Social Consequences of Stroke

The social implications of acquired impairments and disabilities are considerable. Due to the presence of impairment stroke survivors can face many social consequences such as unemployment (Wilz & Soellner, 2009), difficulty at work (Alaszewski *et al.,* 2007), reduction in the ability to engage in valued life activities (Niemi *et al.,* 1988; Drummond, 1990; Gillen *et al.,* 2004) and face fundamental changes to sense of self (Ellis-Hill, Payne & Ward, 2000). Stroke survivors can also experience a loss of independence and their sense of having a social role as they can no longer work or perform duties as a wife, husband or parent, for example (Reed *et al*., 2010). Social stigma can be a common experience for stroke survivors. This is linked with a perceived lack of understanding among others regarding the impairments associated with stroke, society's ableist assumptions and attitudes towards impairments and disability, experiencing embarrassment in social situations and stroke survivors' own fear of being viewed as vulnerable (Reed *et al.,* 2010; Rao *et al*., 2009; Sumathipala *et al.,* 2012). 'Invisible' impairments, such as fatigue or other cognitively based impairments can be viewed as problematic as they lack the apparent acknowledgment and 'considerate' responses of visible markers of disability making visible impairments appear to have certain advantages (Murray & Harrison, 2004). It is unsurprising that depressive symptoms are common among stroke survivors with depression occurring in one third (Knapp, & House, 2010; Broomfield, Laidlaw, Hickabottom *et al.,* 2011). It has been estimated that 33% of stroke survivors experience depression (Campbell Burton *et al.,* 2011) and 20–25% experience anxiety (Hackett *et al.,* 2005). These conditions can remain apparent for several years following an individual's first stroke (Hackett *et al.,* 2005; Campbell Burton *et al.,* 2011). In addition, it is widely accepted that stroke can have a considerable, and negative, impact upon well-being or health

related quality of life (HRQoL) (Hackett *et al.,* 2000; Tengs, Yu & Luistro, 2001; Abubakar & Isezuo, 2012).

Many stroke survivors will rely on their family members for emotional, informational, and instrumental support for daily living (Bugge *et al.,* 1999; Bhogal *et al.,* 2003; Pierce *et al.,* 2006; Denno *et al.,* 2013). Therefore, living with stroke can be both an everyday personal experience and a social one that impacts upon carers and those around the stroke survivor with the most ordinary daily tasks, once taken for granted, becoming wholly conscious social acts. Stroke can create tensions in spousal relationships (Coughlan & Humphrey, 1982; Sjogren, 1982; Teasell *et al.,* 2000; Banks & Pearson, 2004) and, for families, the act of caring can be taxing (Bugge *et al.,* 1999; Bhogal *et al.,* 2003; Pierce *et al.,* 2006) with carers at risk of losing their independence and sense of self (Greenwood *et al.,* 2010; Lawrence & Kinn, 2013). As such the wellbeing of caregivers can decrease due to this burden, the changes that can occur within the family dynamic and within the stroke survivor's personality (Kerr 2001; Greenwood & Mackenzie, 2010; Lawrence & Kinn, 2013). It is no surprise that caregivers are also at risk of anxiety and depression (Denno *et al.,* 2013) and burnout; physical, emotional, and mental exhaustion. Furthermore, stroke can also lead to social isolation and the loss or disintegration of friendships (Astrom *et al.,* 1992; Kvigne, Kirkevold & Gjengedal, 2004; Murray & Harrison, 2004; Northcott & Hilari, 2011). The impact of stroke on the individual, those around them and their social relationships can be considerable.

Stroke and Long-term needs

The personal and social consequence of living with stroke in the long-term has received relatively little attention (Thompson & Ryan, 2009). The majority of data on stroke outcomes is from cohort studies with follow-ups at only 1 year and therefore the majority of data is based on evidence from relatively short-term outcomes (McKevitt *et al.,* 2011). A study by Hackett *et al*., which explored HRQoL 6 years following stroke, concluded that:

> *'… HRQoL 6 years after stroke is acceptable for the majority of survivors, even though many experience ongoing limitations of their physical function. Survivors of stroke do not experience any more pain than the general population, and general health is rated positively by most… Most people are living at home and coping well psychologically, despite ongoing physical disability after stroke'* (2000: 446)

However, this study lacks a qualitative component which could have offered a more in-depth and nuanced understanding of the experiences of long-term stroke survivors in terms of the impact of stroke. Furthermore, other research suggests that, in the chronic, post-hospital phase stroke survivors still have clinical and social needs which remain unmet (McKevitt *et al.,* 2011). A recent report by the, *The Stroke Association*, *Struggling to Recover* (2012), has highlighted that long-term needs are regularly unmet with stroke survivors often lacking suitable information provision, health assessment and social support. This report backs the need for a patient-centred approach to stroke

and underlines the need for improvements in support for stroke survivors living in the community in the long-term. Another recent report by *The Stroke Association* (2013) has highlighted the emotional impact of stroke and called for greater access to clinical psychology services. Due to the presence of this relative gap within the research this study sought to explore the long-term experience of living with stroke and investigate whether stroke survivors are indeed, struggling to recover. In order to explore the long-term experience this study aimed to gain an insight into the personal, subjective experience as opposed to gathering generalizable data.

Stroke and Narratives of Disruption

Due to the potential physical and cognitive impairments which can result from stroke, stroke can be fundamentally disabling. Furthermore, stroke will typically require the survivor to take medication for the duration of their lives, face living with the possibility of stroke reoccurrence as well as experiencing the '*good and bad days'* which characterise chronic illness where good days '*spawn hopes'* and bad days '*dash them'* (Charmaz, 1991: 9). The losses associated with chronic illnesses are considerable. Chronic illness has been theorised as a form of *biographical disruption* (Bury, 1982) and also as a threat to sense of self and self-esteem (Charmaz, 1983; Keppel & Crowe, 2000; Faircloth *et al.,* 2004; Frank, 2004). Stroke has not been absent from such theorising.

Research suggests that stroke survivors will experience a significant disruption as a consequence of the stroke event. Ellis-Hill *et al.* reported that stroke survivors view having a stroke as '*likened to entering a new foreign world*' (2000: 727). Glass and

Maddox (1992) have described life after stroke as a psychosocial transition where unexpected change casts doubt on the sufferer's former assumptions about the world and his or her place in it. Kaufman (1988) has explored the all-encompassing '*biographical labour'* a stroke survivor undertakes in order to make sense of recovery while Becker (1993) made a comparable conclusion in a paper exploring the need for a sense of continuity during the recovery period after stroke. Becker and Kaufmans' (1995) well known qualitative examination of stroke further exposed the biographical process which follows the event of a stroke. According to Beck and Kaufman a stroke survivor's experience of rehabilitation can be characterised by frustrations and uncertainty due to the ambiguous prognosis they are presented with and the onus on active performance in rehabilitation. According to Beck and Kaufman stroke survivors can allow themselves to believe that working hard in rehabilitation will eventually lead to a recovery only to be left frustrated and disillusioned when a full recovery fails to materialise.

Stroke as Biographical Disruption

Michael Bury's concept of biographical disruption was first presented in 1982. Bury observed that chronic illness represented a *disruption:* the suddenness of chronic illness significantly disrupts and governs the individual's life*,* producing a feeling of ambiguity and ultimately leading the questioning of taken-for-granted assumptions about the world. The individual must rethink their biography and sense of self, requiring the enlistment of resources to counter-act or respond to the life disruption.

Bury's original article focused on rheumatoid arthritis patients. He noted that the anguish felt by individuals regarding their illness was based on the cultural belief that arthritis is a condition of older people and as such being diagnosed with arthritis at a younger age constituted '*premature aging'* (Bury, 1982: 171). What participants saw as normal ageing (a taken for granted assumption), was questioned and thus the participant's conceptualisation of a future biography was disrupted as were their everyday lives. Not only is the individual faced with disruption in their everyday lives and the task of renegotiating their biography, the individual also faces symbolic and cultural issues: different conditions hold different cultural connotations which can influence how the individual sees themselves, and how they believe others view them. This can result in the fear or experience of stigma stemming from the cultural beliefs regarding chronic illnesses. The concept of biographical disruption has had a significant impact on theorising concerning chronic illness and disability spawning adaptations such as biographical abruption; '*a distinctive sense that the diagnosis is a 'death sentence' and life is already over'* (Locock, Ziebland, & Dumelow, 2009: 1043). However, some have challenged whether biographical disruption is always an appropriate lens through which to explore chronic illness (Hubbard, Kidd & Kearney, 2010) while others have created positive adaptations to the concept. One example is 'biographical flow' in which the world continues its '*ongoing flow of events, actions, reactions and self-preservation of identity as these are placed in the pre-existing biographical context of the [stroke] survivo*r' (Faircloth *et al.,* 2004: 245) Similar adaptations are 'biographical reinforcement' and 'biographical continuity' in as presented within Carricaburu and Pierret's (1995) exploration of the experience of AIDS/HIV survivors.

The theory of biographical disruption has become interwoven into research on stroke as a sudden and chronic illness (Becker, 1993; Becker & Kaufman, 1995; Kaufman, 1988; Ellis-Hill, 1997; Hill, 1997; Ellis-Hill *et al.,* 2000). This process has led to some claiming that biographical disruption has formed a 'grand narrative' of literature on stroke recovery (Hýden, 1997). However, other research on stroke has observed the possibility of curtailing both the biographical and physical impact of stroke (Faircloth *et al.,* 2004, Pound *et al.,* 1998a). Pound *et al.* (1998a) have proposed that stroke survivors with prior experience of stroke or other debilitating life circumstances attempt to normalise the stroke event and as a consequence view it as an inevitable part of life thus contradicting the view of stroke as biographical disruption for such individuals. Faircloth *et al.* (2004) have also suggested that biography is not always disrupted but that stroke survivors can experience 'biographical flow' as mentioned above. By focusing on the long-term experience of living with stroke this study can help to unpick whether bodily impairments do become normalised or whether stroke survivors do linger in a 'foreign world'.

Body and Self

Doolittle (1992) has suggested that for stroke survivors the body can become objectified during the process of recovery with an affected limb, for example, being viewed as an object which requires manipulation. Within Doolittle's study the participants were faced with limbs that failed to operate as they previously had; what was once straightforward had become problematic. This resulted in a continual conversation with the effected limb, willing it to function satisfactorily. Such conceptualisations have been echoed in other studies. For example, according to Ellis-Hill *et al.* (2000) during the process of stroke recovery *'[t]he body, separated from the*

self, takes on the nature of an object' (2000: 728); Faircloth *et al.* (2004) have also discussed the process of a mind-body disconnection within their study on stroke survivors. This suggests the sense of wholeness between the body and self can come under threat due to the sudden presence of impairment. By focusing on the process of embodiment this study aims to further investigate and explore what occurs to the socially shaped body and the essence it holds within the identity of long-term stroke survivors.

Stroke survivors typically acquire disability in an instant which can rupture the relationship between themselves, their bodies and the social world. Furthermore, people with disabilities are often characterised by their perceived 'otherness' (Hughes, 2002) within the wider cultural milieu and as such acquiring disability not only shifts the individual's relationship with the social world but can also result in their body bearing the cultural weight of society's assumptions, presumptions and fears of disabled bodies (Edwards & Imrie, 2003; Swain & French, 2000; Kitchin, 1998). However, the narrative of disruption is somewhat focused on the external without accounting for the process of embodiment: it does not fully account for the body as located within the social and the social within the body. Individuals do not exist in isolation but within a complex and layered social world in which they must negotiate their physical environment, the people, groups and institutions within the social world and the laws and unwritten rules that govern the social world. As individuals negotiate the social world it impacts on their understanding of it and they impact on it. In order to explore the process of embodiment within this study the 'theoretical toolkit' offered by Pierre Bourdieu was utilised.

1.3: PIERRE BOURDIEU & THE 'THEORETICAL TOOLKIT'

In order to study the experience of living with stroke in the long-term or chronic phase, it was deemed useful to utilise a theoretical framework designed to aid understanding of how the social world and social body interact with and impact on each other; to understand the process of embodiment. Many of the key concepts such as habitus, capital, symbolic violence and doxa within the voluminous body of work produced by Bourdieu have been utilised in research exploring the tensions between able, healthy bodies and disabled, ill bodies and how these bodies are enmeshed within and shaped by wider structural and cultural factors (Edwards & Imrie, 2003; Gibson *et al.,* 2007; McKeever & Miller, 2004; Kelly 2010). Bourdieu's concepts are grounded in the body (Shilling, 1993) and are, therefore, especially salient in ethnographies of embodiment. According to Bourdieu bodies are (re)produced socially, educated in ways which are observed to be of value within particular social-spatial fields:

> "...*practices are incorporated within the body, only then to be regenerated through the embodied work and competence of the body"* (Crossley, 2001: 106).

Therefore, within Bourdieusian theory the body is viewed as a '*bearer of value*' (Edwards & Imrie, 2003: 240). His theoretical framework was therefore deemed an appropriate and useful guide to explore the perceptions and experiences of long-term stroke survivors within this thesis.

1.3.1: The Toolkit Metaphor

Over the course of Bourdieu's career he developed and employed a complex interwoven set of theoretical concepts which he referred to as his 'thinking tools' (Grenfell, 2010). These thinking tools were developed out of Bourdieu's creative and inventive use of key thinkers whose work grappled with themes of structure and or agency such as Levi-Strauss, Durkheim, Weber, Marx and Mauss as well as the philosophies of Bachelard, Heidegger and Wittgenstein, who, in an interview in 1985 Bourdieu stated was '*a kind of saviour for times of great intellectual distress* (Bourdieu, 1990: 9). Having such thinking tools to hand, researchers can utilise Bourdieu's work as though it were an abstract toolkit. Just as individual or multiple tools can be used to solve a 'do-it-yourself' dilemma within a household, Bourdieu's concepts can be utilised to solve an academic dilemma. Indeed the terms toolkit and 'toolbox' have been used to describe Bourdieu's work elsewhere (Husu, 2012; Silva & Warde, 2010; Atkinson, 2010). Silva and Warde, however, do add a warning to this view of Bourdieu's work:

> *"[t]o review Bourdieu's opus as a giant sociological toolkit would reveal enormously versatility. There perhaps is the rub, for one can do both good and bad things with his instruments; they allow both congenial and objectionable ways of approaching the analysis of the social world"* (2010: 295).

Care does need to be taken when utilising this versatile and complex set of tools. A further key issue to note is that these thinking tools are not to be conceptualised solely as a series of interrelated ideas but also as a method. The core use of this method within this thesis is as *a way of thinking*. Furthermore, according to Bourdieu, theoretical concepts should be viewed as '*polymorphic, supple and adaptive, rather than defined, calibrated and used rigidly*' (Bourdieu & Wacquant, 1992: 23). Therefore, this toolkit is adaptive with permission given by its creator to use the tools at their disposal creatively. It is with this spirit in mind that this thesis was undertaken.

1.4: SUMMARY

Disabilities and chronic illnesses are problematic concepts with considerable overlap and distinctions. The aftermath of a stroke can result in an individual straddling the lines between chronic illness and disability. However, despite the bodily and social impacts of stroke this condition is often sectioned off within the literature in which a grand narrative of disruption has come to characterise understanding of it. This grand narrative, while providing a deepening understanding of the personal and biographical experience of stroke does not fully account for the process of embodiment. Out with the stroke literature, within the wider literature on disabilities, there is an increasing awareness of the need to account for the process of embodiment and the potential this holds for increasing understanding of the experience of disability and the body. In order to increase understanding of stroke, particularly in the long-term, this thesis aimed to explore the experiences and perceptions of stroke survivors through the lens of embodiment. To undertake this exploration this thesis adopted an approach informed by the theoretical toolkit provided by Bourdieu's sociology in which the body

represents a bearer of value and plays a vital role in the access of resources, status and distinction. Bourdieu's theoretical toolkit is wide ranging with many interrelated concepts. The vast and growing literature which utilises so called Bourdieusian theory often restricts analysis and discussion to three core thinking tools of habitus, capital and field. However, this can often lead a shallow, misplaced or ridged use of the toolkit. Therefore the succeeding chapter will provide a comprehensive outline of the contents of the toolkit in order to provide the reader with a more in-depth understanding of Bourdieusian thinking.

CHAPTER 2: THE BOURDIEUSIAN TOOLKIT

2.1: INTRODUCTION

This thesis aimed to explore the experiences and perceptions of long-term stroke survivors through the lens of disability and embodiment. A core aspect of this approach was the utilisation of Bourdieusian thinking. As discussed within the previous chapter Bourdieu produced a voluminous theoretical toolkit designed to breakdown the false dualism between agency and structure. The purpose of this chapter is to provide an outline of this toolkit in order to endow the reader with a comprehensive understanding of both the key and more minor, less well known concepts which inform Bourdieusian thinking.

2.2: PIERRE BOURDIEU

Pierre Bourdieu, born in the Béarn region of south eastern France in 1930 (Robbins, 2000: 2), became arguably the most eminent sociologist of the latter stages of the 20th century with his influence spanning numerous countries and academic disciplines. In the mid-20th century there was considerable debate within sociology and other social sciences which centred on two differing theories which, in simplistic terms, can be split into those that examined and theorised social life on a societal level in order to expose the underlying structure of society and thus aligned with structuralist thought, and those theories which focused on the actions of individuals and therefore on agency. Bourdieu saw the split between these two camps as an *'absurd opposition between individual and society'* (Bourdieu, 1990a: 31). Bourdieu's attempt to reconcile the individual, the body, and society is in many ways the crux of his work.

Bourdieu conducted a considerable amount of ethnographic exploration and fieldwork and was a prolific writer whose work is wide-ranging including research into the media (Bourdieu, 1998), language (Bourdieu, 1991) and the role of social class within sport (Bourdieu, 1978, 1984, 1993). However, this considerable volume of work has been accused of being difficult to access as Laberge and Kay express:

> "*Bourdieu's writing style is tortuous. His sentences are often long and abstract, and charged with polemic, paradox, multiple negation and pu*n" (2002: 261).

However, as Jenkins states, Bourdieu is '*enormously good to think with'* (2002: 11). The exciting aspect of Bourdieu's concepts is their usability in studies concerned with how individuals and individual bodies interact with, shape and are shaped by the social world. The challenge Bourdieu imposed upon himself was to create a theoretical framework which could guide the investigation of the continually transforming *zusammenhang*[2] of social activity which transcends the perceived dichotomy between structure ('outer') and agency ('inner'). In this sense Bourdieu's work holds considerable similarity to the theoretical ruminations of Norbert Elias. Like Bourdieu, Elias sought to explore the interwoven nature of individuals, bodies, society and action or practice as he asserts:

> *"[c]ivilization . . . is not a process within a separate sphere of 'ideas' or 'thought'. It does not involve solely changes of 'knowledge',*

[2] The German word *zusammenhang* is an economical word for describing a hanging-together of entities that forms a context for each or a relationship that exists between interlocking or interconnected parts.

> *transformations of 'ideologies', in short alterations of the content of consciousness, but changes in the whole human makeup, within which ideas and habits of thought are only a single sector. . . .Every investigation that considers only the consciousness of men, their 'reason' or 'ideas', while disregarding the structure of drives, the direction and form of human affects and passions, can be from the outset of only limited value"* (Elias, 1994: 485-486 [cited in Paulle, van Heerikhuizen & Emirbayer 2011]).

Bourdieu's work also contains '*conceptual linkages*' to that of Michel Foucault (Schlosser, 2012: 32). Standing on the shoulders of great thinkers such as Durkheim, Heidegger and Merleau-Ponty, all three authors placed prominence on relational and processual reasoning, seeking to overcome the dualisms of structure and agency and each utilised a set of interwoven concepts within their work. Within Bourdieu's framework these key concepts include a conceptual triad of habitus, capital and field. While one can discuss these concepts thematically they are interconnected and must be understood in this manner as Bourdieu and Wacquant comment:

> *"[s]uch notions as habitus, field, and capital can be defined, but only within the theoretical system they constitute, not in isolation"* (1992: 96).

While the succeeding section of this Chapter has been structured to define habitus, capital and field, and other related concepts, in turn it will be clear that none of these concepts can be defined clearly without reference to the others.

2.3: THE CONTENTS OF THE TOOLKIT

As mentioned in the previous chapter Bourdieu's thinking tools can be thought of collectively as constituting an abstract toolkit. The purpose of this section is to outline some of Bourdieu's key thinking tools. As mentioned above the concepts Bourdieu utilises are interwoven and as such the explanation of one of these concepts will require reference to the others. Therefore, brief explanations of habitus, field and capital, are provided below in order to provide the reader with a foundational understanding of these concepts before they are considered in greater depth.

Habitus: socially learned dispositions or ways of acting and thinking which individuals develop through the experiences of everyday life across the life span and is anchored on an individual's access to, and accumulation of, capital. Such dispositions are, in day to day situations, responsible for the taken for granted actions and thoughts of the individual. Habitus is neither entirely fixed nor fluid and thus could be described as thixotropic[3]. For instance, an individual's principle dispositions will be laid down through childhood experiences, however across the life span further experiences steadily amend the habitus and certain, significant, experiences may result in a considerable amendment yet, over time the habitus returns again to a semi-solid state.

Field: often equated with social space, a field is a structure of positions comprising individuals, groups and institutions which compete to maximise their position (Maton, 2005). Within this thesis field and the term socio-spatial field will be used

[3] Thixotropic: retaining a semi-solid state unless shaken or stirred (high disturbance) which causes the substance to become fluid. The substance returns to a semi-solid state once left undisturbed

interchangeably. The structure of the field is born of the relations between those within it and across the individuals and groups within it. Fields are often viewed as empirically obvious groups or institutions; the relations within the work place for example. However, while the relations of a field can emerge from such groups a field is more than a clear and outlined space; it is '*more than the sum of its parts'* (Maton, 2005: 689). What defines a field is action or practice across and between individuals, groups and institutions making fields as semi-solid as habituses. For example, a banker exists within the field of his own office and institution but, through shared practice, is also connected to the larger field of banking beyond his own institution and the individuals he encounters on a regular basis. This fictional banker would also belong to other fields such as a sports club, for example. The social world can be viewed as a matrix of synchronic and changeable fields and of interlinked fields. An individual can be part of a multiple number of fields simultaneously and has the potential to hold a high status in one field and a lower status in another. This is crucial to the concept of capital.

Capital: there are three key forms of capital; economic, social, and cultural. The forms of capital can be accumulated and transferred from one field or individual to another (Navarro, 2006: 17). Economic capital refers to monetary assets. Social capital concerns the resources that can be gleaned from the individuals, groups and institutions a person, group or institution is linked to. Cultural capital refers to knowledge, tastes, values and abilities. At a societal level social classes can distinguish themselves through taste and as such cultural capital can play a crucial role in symbolic societal power relations. Economic capital (material) can be turned into social and cultural forms of

capital creating subtle forms of inequality. For Bourdieu an individual's position within the wider societal field is not defined by social class, per se, but by the relative amount of social, economic and cultural capital they hold within the fields they occupy. This means that social or cultural capital deployed with the right competence can result in economic capital and improved position within a given field or fields.

In succinct summary, over time an individual is socialised in a field or matrix of fields in which capital of various forms are at stake. This individual accumulates capital. The individual's experiences within the various fields and the capital accumulated are internalised and embodied, enabling the development of a series of dispositions forming the habitus which then, in turn, impacts upon the actions and practice of the individual within these various fields. The habitus thus provides '*le sens pratique'*, that is, a *'feel for the game'* (Bourdieu, 1990b: 52) within these fields.

2.3.1: Habitus and Dispositions

Habitus, in simple terms, is '*the basic stock of knowledge that people carry around in their heads as a result of living in particular cultures or subculture*s' (Cunningham, 1993: 1 [cited in Edwards & Imrie, 2003]). It is the product of the socialisation of the body; it is what links social structures and social practice. However, habitus is a concept with considerable power to produce bamboozlement; the notion can be '*revelatory and mystifying, instantly recognizable and difficult to define, straightforward and slippery*' (Maton, 2010: 49). This conflicting nature is partially due to its key purpose, that is, to overcome the perennial dichotomies and dualisms which

have buttressed considerable philosophical and sociological understandings about the complex workings of the social world and the social agent.

Bourdieu states that habitus is '*an old Aristotelian and Thomist concept*' which he *'completely rethought*' (Bourdieu, 1990a: 10) and goes on to cite Merleau-Ponty, Husserl and Heidegger as key thinkers to have utilised the concept of habitus within their work. Bourdieu's conceptualisation of habitus operates as a trinity in that it is a structured and structuring structure; '*structured structures predisposed to function as structuring structures…*' (Bourdieu, 1990b: 53). Habitus is a) structured by past and present experiences and circumstances, b) structuring due to its role in enabling action within the present and the future (Maton, 2010) and it is c) a structure; a '*system of durable, transposable dispositions*' (Bourdieu, 1990b: 53). Dispositions are fundamental to the operations of the habitus as they are, in short, the social agents '*feelings, thoughts, tastes and bodily postures*' (Reed-Danahay, 2005: 107). Bourdieu states '*I am talking about dispositions acquired through experience, thus variable from place to place and from time to time*' (1990a: 9). Therefore, dispositions are not all acquired through conscious learning but also acquired unconsciously as individuals move through differing spaces and places and interact with others. The concept of 'dispositions' is crucial to the concept of habitus and this concept is potentially the most cogent and difficult to dispute of Bourdieu's thinking tools due to the inherent common-sense and logic of it. As Bourdieu himself states, '*to deny the existence of acquired dispositions, in the case of living beings, is to deny the existence of learning'* (Bourdieu, 2000: 136).

It is this system of dispositions, or '*incorporated set of 'practical taxonomies''* (Lane, 2000: 100), which operate within, and amalgamate to form, the habitus and this habitus is developed by continual interaction with the external world producing mental schemes which guide an agent's practice or action. This means the development of one's dispositions, and therefore habitus, are dependent on the circumstances of one's background, schooling and so on. Crucially, the habitus is thus historical yet it also malleable as one's dispositions can alter or, perhaps more appropriately, mutate, across an individual's life course due to the vast array of situations one may find one's self in and thus the copious and varied experiences one is likely to encounter over the years of one's life. As such individuals inherit dispositions as well as acquiring them over time through exposure to differing socio-spatial fields. Dispositions are both generative and transposable:

> *"...they are capable of generating a multiplicity of practices and perceptions in fields other than those in which they were originally generated"* (Bourdieu, 1991: 13).

Habitus also enables '*spontaneity without consciousness or will*' (Bourdieu, 1990b: 56). As Bourdieu explains:

> *"[y]ou need only think of the impulsive decision made by the tennis player who runs up to the net, to understand that it has nothing in common with the learned construction that the coach, after analysis, draws up in order to explain it and deduce communicable lessons from it. The conditions of rational calculation are practically never given in*

> *practice: time is limited, information is restricted etc. And yet agents do, do, much more often than if they were behaving randomly, 'the only thing to do"* (1990a: 11).

Crucially then habitus works in relation to capital and field to enable practice. As Bourdieu's formula goes [(habitus) (capital)] + field = practice (Bourdieu, 2008 [1979]: 101). Maton provides a succinct 'unpacking' of this equation:

> "...*practice results from relations between one's dispositions (habitus) and one's position in the field (capital), within the current state of play of that social aren*a" (2010: 51).

This may at first seem circular and deterministic; a theory destined to brand individuals as social or cultural 'dopes'. However, this is not the case. Bourdieu reports that his thinking began with a key question in mind: '*how can behaviour be regulated without being the product of obedience to rules*?' (Bourdieu, 1990a: 65). As already stated Bourdieu's aim was to transcend the dichotomy between agency and structure in order to expose the ways in which the subjective and objective relate and interact as co-producers of practice. As Bourdieu states '*action is not the mere carrying out of a rule, or obedience to a rule. Social agents… are not automata regulated like clocks…'* (Bourdieu, 1990a: 9). Rather, due to the relationship between the habitus and field, social agents develop a '*feel for the game'*; in day to day life we would consider ourselves individuals or free agents however, for the most part, each of us make decisions and conduct ourselves on the basis of assumptions we have regarding other 'individuals' and the external environment we find ourselves in. We were not born

with these assumptions they have developed over time enabling the accumulation of a system of dispositions dependent on our own unique experiences. Yet these assumptions can be challenged by new experiences and the social agents themselves can challenge what they perceive to be society's unwritten rules and regulations. As Robbins states;

> *'[A]ll humans inherit dispositions to act in circumscribed ways. In this sense they possess an inherited concept of society which they then modify, generating a new concept which is apt for their conditions and experience… For Bourdieu, the habitus embodies the attitudes which we inherit,* ***but does not constitute a stimulus which conditions how we must behave****.' (*Robbins 2000: 27 and 29 [emphasis added])*.*

Furthermore, it is not only the habitus which evolves or mutates over time, fields are also subject to such metamorphosis. The continual interactions between habitus and field are the sites where social structures are both perpetually produced and reproduced over time but also the sites in which such structures can be challenged and become modified – however change can often be a slow process. On the one hand habitus and field interact to maintain unwritten rules and yet these same interactions enable change. This is the key to both stability and social evolutions within society (Maton, 2010; Robbins, 2000).

Habitus and Field: Cases of Fish Both In and Out of Water

According to Bourdieu and Wacquant:

> "...*when habitus encounters a social world of which it is the product, it is like a 'fish in water': it does not feel the weight of the water and it takes the world about itself for granted*" (1992: 127).

In order for the individual to manoeuvre within a field with relative ease the individual's habitus must be in tune with the eidos of that field. Maton explains that the habitus and field '*do not match perfectly, for each has its own internal logic and history*' and crucially this enables the '*relationship between the structure of a field and the habituses of its members to be one of varying degrees of fit or mismatch*' (2010: 57). So while a high degree of fit enables the individual to feel like a 'fish in water' mismatch can lead to a feeling of being a 'fish out of water' when one encounters a social field to which one's current dispositions are not accustomed. For a simple example a London based business executive who was brought-up within a middle-class home, and educated in a private school could easily feel like a 'fish out of water' if, for whatever reason s/he were to find her or himself at a party in deprived urban estate on the outskirts of Glasgow because the system of dispositions that constitute this individual's habitus are likely to be dissimilar to those of her or his fellow party-goers. However, the feelings of being a 'fish out of water' may be unconquerable *or* short-lived depending both on the individual agent, the others s/he interacts with and the field they occupy at the time. Furthermore, new experiences can alter one's dispositions. For another simple example, an academic's first time at a conference may be a daunting experience. However, as more conferences and symposiums are

attended the academic's dispositions progressively adapt to that type of situation making it less foreign; interactions between such environments and the habitus provide that academic with the dispositions which enable them to develop a 'feel for the game'. This is because habituses are '*permeable and responsive to what is going on around them*' (Reay, 2004: 434) and as Sayer explains:

> "*later experiences can modify the habitus and produce new dispositions, and skills, enabling people to react in new ways… they may feel comfortable in contexts where they might not have done earlier*" (2005: 25).

Therefore, habitus is both stable yet alterable. The relative stability of habitus can create a tension between habitus and field if, for whatever reason, a field an individual occupies undergoes a considerable change. This is captured by the hysteresis effect.

Habitus and the hysteresis effect

As discussed above the habitus is somewhat pliable and modifiable through the development of new dispositions. When an individual's habitus encounters a new field it can generate change both within itself and within the field. However, as mentioned above the relationship between habitus and field is always a matter of match or mismatch: the two can be '*out of sync*' (Maton, 2010: 59). As Maton explains:

> *"[b]ecause its dispositions are embodied, the habitus develops a momentum that can generate practices for some time after the original conditions which shaped it have vanished… though the habitus is shaped by*

ongoing contexts, this is slow and unconscious – our dispositions are not blown around easily on the tides of change in the worlds we inhabit" (ibid)

Bourdieu's classic ethnographic work on the Kabyle Berbers of northern Algeria provides a good example of this. The colonisation of Algeria by the French resulted in sudden technological and societal advancements such as a change in understanding of time and monetary exchange. Despite this the Kabyle people maintained their traditional practices for some time. Bourdieu argued that this was because their dispositions were formed within a particular historical cultural milieu and could not be expected to change at the rate of change foisted upon Algeria at large by the French (Maton, 2010). Rapid changes with a field can constitute a catastrophic change which can render an individual's dispositions incapable of providing them with a feel for the game within that field. There is a disconnect between field and habitus. Bourdieu conceptualised this kind of disconnect as the '*hysteresis effect*' (Maton, 2010). The hysteresis effect is habitus out of time or place; when there is a catastrophic change in the structure and conditions of a field, the dispositions embodied in the habitus are no longer adequate to comprehend and move within that field. Hysteresis can also occur if someone encounters a field to which their habitus is markedly unaccustomed, for example refugees or immigrants from Asian countries attending a school within a Western country as explored by Dumenden and English (2012). New dispositions must be acquired for the individual habitus to attain a feel for the game within this altered or new field.

Habitus and the Body

Habitus is embedded in the body and Bourdieu used the word '*hexis*' to refer to the embodiment of the social world within habitus. Our bodily movements are learned in concurrence with the dispositions typical of the group or social class to which we were born. This enables the individual to navigate through culturally constructed and informed spatial structures. The concept of *bodily hexis* signifies the numerous socially instilled ways a social agent moves (their posture, gait, gestures etc.) within the world around them. Bourdieu describes the concept as:

> *"...political mythology realized, embodied, turned into permanent dispositions, a durable manner of standing, speaking, and thereby of feeling and thinking…"* (Bourdieu, 1977: 94).

Thus the bodily hexis and habitus are deeply interwoven. Bourdieu states that '*the way people treat their bodies reveals the deepest dispositions of the habitus*' (Bourdieu, 1984: 190). The way an individual moves and gestures or even dresses can reveal implicit and explicit information about him or her and his or her relationship to the world. The embodiment of the social world and the significance of the body in the acquisition of power and status are encapsulated within the concept of physical capital discussed later in this chapter.

The Problematic Notions of Habitus Types and Collective Habitus

As alluded to above, those who have accumulated their dispositions under similar circumstances and influenced by similar structures, for example, those from the same

class background, will exhibit similar practices due to acquiring similar dispositions. Such individuals will typically be in a position to relate to and understand each other's perspective with greater ease than someone whose background is markedly different. These habituses with similar dispositions are developed due to these individuals interacting with the same or similar socio-spatial fields as they develop '*schemes of perception*' in line with the social groups they interact with (Ingram, 2011: 289). Sulkunen provides a neat explanation:

> "...*the various practices of living among a certain class or group are harmonised and homologized in accordance with its specific living conditions … This harmonization and homologization is brought about by a common habitus, a generative principle, modus operandi… the habitus integrates different aspects of life style: taste in dietary patterns, housing patterns, style of dressing, aesthetic codes, etc. into a consistent whole. Thus the same principles (or meaning structures) that appear in working class clothing should be found in its dietary patterns and artistic tastes*" (1982: 108).

The notion of types of habitus based on class and taste rests at the heart of what is probably Bourdieu's most well-known and cited text; *Distinction: A Social Critique of the Judgement of Taste* (1984). Due to these general similarities within such groups Bourdieu used the term 'class habitus' to denote '*the internalised form of the class condition and of the conditionings it entails'* (1984: 101). Within *Homo Academicus* Bourdieu also speaks of an '*academic habitus*' (1988: 99) referring to the pedagogically acquired mental schemas associated with those enmeshed within academic fields such

as University based researchers. The notion of individuals sharing a similar type of habitus leaves Bourdieu open to accusations of determinism by those who conflate the notion with the idea that individuals can hold an identical habitus and therefore identical and mechanical action. However, Bourdieu himself consistently argues against the idea of individuals having the same habitus:

> *"… in the interaction between two agents or groups of agents sharing the same habitus (say A and B) everything takes place as if the actions of each of them … were organised in relation to the reactions they call forth from any agent possessing the same habitus … so they objectively imply anticipation of the reaction which these reactions in turn call forth …**But the teleological description according to which each action has the purpose of making possible the reaction to the reaction it arouses… is quite naïve** as the mechanistic description which presents the action and the riposte as moments in a sequence of programmed actions produced by mechanical apparatus … It is necessary to abandon all theories which explicitly or implicitly treat practice as a mechanical reaction, directly determined by the antecedent conditions and entirely reducible to the mechanical functioning of pre-established assemblies…"* (1977: 73 [emphasis added]).

The concept of habitus, in conjunction with field, is used by Bourdieu to explore collective action and the perpetuation of social groups as well as individual action and social change. While individuals can have similar habituses Bourdieu states clearly that '*[j]ust as no two individual histories are identical so no two individual habituses are identical*' (1993a: 46).

Individuals can exhibit similar behaviours and interact with ease due to the collective understanding of a group but the habituses within these individuals are not identical. This retains agency while accounting for norms, affinities and the role of structure in producing action and practice. Thus when Bourdieu speaks of a 'class habitus' and 'academic habitus' he uses these terms, as Atkinson notes, as a '*label for describing **family resemblances** between individual's situated in a certain section of social space'* (2011: 338 [emphasis added]).

Yet, this potential for a shared habitus types is somewhat problematic in terms of how it has been utilised within empirical research. Reay remarks in her article '*It's all Becoming a Habitus'* that '*there is an increasing tendency for habitus to be sprayed throughout academic texts like 'intellectual hair spray'*[4] (2004: 432). It can be all too easy to take empirical data on any given group, be it a set group or a momentary congregation and state that the individuals involved have a 'X' or 'Y' habitus or as Maton states '*the tendency for habitus to proliferate adjectives'* (2010: 63). For example, Parkin and Coomber (2010) in a study on public drug use proclaim a *'public injecting habitus'*, Rimmer (2010a and 2010b) describes a '*musical habitus'*, and Gould (2009) suggests an '*emotional habitus'* in her theorisation of the practice of '*Act Up*', an aids activism group. In this manner everything can become a habitus, or habitus is utilised merely to define a group of similar people or individuals undertaking similar activities. Within this thesis there could be the potential to talk of a 'stroke surviving habitus' or 'disabled habitus' yet this would undoubtedly be the result of missing the

[4] Reay has taken the term '*intellectual hair spray*' from Hey. V (2003) *Identification & Mortification in late modernity: New Labour; alpha femininities and their dis/contents*, a keynote address at the *International conference of Gender and Education* at the University of Sheffield.

point that stroke, and disability, can have differing effects both physically and cognitively and occur to people from any background. This ultimately means that each stroke survivor will have varied impairments to come to terms with and different support structures in place. They may acquire similar experiences but the effect this would have on each individual's dispositions, and therefore habitus, would ultimately depend on their own individual circumstance. To talk of a 'disabled habitus' would be reductive and potentially offensive in that it would perpetuate the view that people with disabilities are a homogenous group. Viewing people with disabilities in this manner would ignore differences between disabled people, for example socio-economic status, education, gender, ethnicity, sexuality, age and the particular nuances of individual impairments and thus the personal experiences and perceptions of living with disability (Watson, 2004).

It is perhaps more helpful to talk of people having certain *dispositions* which enable individual's to act in similar ways at *specific* times and under *specific* conditions. Saying that individuals within groups have an X or Y habitus reduces agency and diminishes what the concept of habitus offers. Perhaps this is a case of not seeing the trees (dispositions) for the woods (habitus). Rather than musical habitus, for example, It might be more appropriate to speak of musical dispositions as to speak of a musical habitus could suggest that the individual has a narrow set of dispositions which of course potentially reduces their capacity for creative action. What about a hypothetical individual who can paint, act, and play a musical instrument all well and creatively? Does this person have a painting habitus, an acting habitus or a musical habitus? You could say this person has a 'creative habitus' because they are creative, however just

because the individual excels in certain arts does not mean the individual is creative at all times, they could be an awful writer or dancer, for example. Dispositions within the individual's habitus enable the individual's creativity in particular contexts but that does not define that individual's habitus within *all fields*. The possibility of being musical can be encoded into the individual in the form of dispositions and when that individual encounters a field within which these dispositions are of worth and value this possibility is actualised; however within other fields these dispositions are possibly not of worth, or even use, and other dispositions will be called upon[5]. A key point here is that placing a categorising term in front is the word habitus loses sight of Bourdieu's formula: [(habitus) (capital)] + field = practice. As Bourdieu and Wacquant state '*[i]t is only in the relation to certain structures that habitus produces given discourses or practices'* (1992: 135).

The dispositions which inform practice are not solely governed by the habitus but also by capital and field; it is not that the individual has a *public injecting* habitus, for example, it is because the field(s) they are occupying or moving through interact with the habitus and result in public drug taking *practices*. Certain dispositions will be called upon in order to manoeuvre within a given field and other dispositions, while still inherent within the individual's habitus, will not necessarily be called upon. The individual therefore does not have a public injecting habitus but is partaking in public drug using practices due to the dispositions that are actualised by the contact between the individual's habitus and the field(s) occupied. Placing habitus at the front of a

[5] Of course dispositions acquired through musical pursuits could turn out to be of considerable use and thus value in fields which appear to be distant and removed from what one would commonly associate with music. This does not prove the existence of a musical habitus, however, rather it gives a nod to the transposable nature of dispositions and that the habitus enables creativity in practice and action.

practice is ultimately an act of '*bestowing gravitas without doing any theoretical work*' (Reay, 2004b: 432) or acquiring '*distinction by proxy*' (Howland, 2013: 326) and furthermore undermines the concept of habitus making it appear deterministic; so and so acts like that because they have an X or Y habitus. If we wish to understand the interaction between the individual and the multiplicity of fields which constitute society perhaps dispositions need to be given greater prominence in analysis.

Furthermore, the propensity for scholars to call upon habitus to define a type of activity also ignores a sparsely used, yet potentially advantageous Bourdieusian concept, *conatus*. This concept is referred to briefly only in *Homo Academicus* (1988), *Practical Reason* (1998), *Pascalian Medications* (2000), and within *Concluding Remarks*, a book chapter Bourdieu wrote for the edited book, *Bourdieu: Critical Perspectives* (1993) and *The Contradictions of Inheritance,* one of his contributions to *The Weight of the World: Social Suffering in Contemporary Society* (1999). The heritage of conatus rests in the Latin for 'endeavour' or 'striving'. Bourdieu defines it as:

> "*… that combination of dispositions ... associated with a particular … social position which inclines agents to strive to reproduce at a constant or an increasing rate the properties constituting their social identity, without even needing to do this deliberately or consciously … It is not true to say that everything that people do or say is aimed at maximizing their social profit; but one may say that they do it to* ***perpetuate or to augment their social being****"* (1988: 176 [emphasis added])

> "*...both habitus and field . . . are the site of a sort of conatus, of a tendency to perpetuate themselves in their being, to reproduce themselves in that which constitutes their existence and their identity"* (1993: 274).

Conatus is therefore striving not only to (re)produce but also to develop and enhance the self in response to *certain social conditions*. It is thus linked to the *illusio* or social libido (outlined below) as it exposes personal investment, realized only in the relation between habitus and field. Therefore, conatus acknowledges the potential for a set of dispositions, as opposed to the whole habitus to come together to influence practice within certain fields. Conatus could, with relative ease, be utilised in the theorising around the musically inclined or even drug addiction. While taking drugs may not be perceived as a positive pursuit, within the lives of those with addiction the act of appeasing that addiction could, in that moment, be an act of reproducing themselves and augmenting their social being[6]. Habitus is an incredibly useful concept however notion of habitus types used within empirical and applied research is perhaps the result of somewhat simplistic theorising or shallow reading of Bourdieu's body of work.

A similarly problematic use of Bourdieu's concept of habitus is that of 'collective habitus', for example, 'institutional habitus', such as a school, and 'family habitus'. As Will Atkinson (2011) argues in his critique of the subject, such uses of the concept reduce habitus to expectations and assumptions and conflate the products of habitus (practice) with aspects of habitus (dispositions). Furthermore the concept of collective

[6] Obviously this statement is operating at a hypothetical level as the author has not gathered such data nor conducted such an analysis. This statement has been made merely to highlight that many researchers who use Bourdieu appear to theorise solely through habitus which can be problematic and misses the potential of other aspects of Bourdieu's theoretical toolkit.

habitus endows the institution or group with its own schemes of perception and thus with its own agency which is problematic as Atkinson explains:

> *"...one simply cannot argue that a supra-individual entity – whether the school or family or, following the reasoning, why not such things as trade unions, companies or states? – 'experiences', 'perceives', 'has assumptions', is 'predisposed' toward anything or, indeed, acts (in the sense that its habitus generates 'practices') at all. Only individuals possess those traits and capacities. Ultimately this is because the habitus and all its components (dispositions, schemes of perception, etc.) are necessarily corporeal or, to put it in broader terms, organic; that is, rooted in the dense mesh of neural networks formed through the strengthening and weakening of synaptic connections through experience"* (2011: 337).

For Atkinson what those who utilise the notion of collective habitus appear to be describing is not habitus but doxa: '*the generalised sense of 'what is done'* (Atkinson 2011: 340) within specific socio-spatial fields. The doxa, which is explained in greater detail later, is both internal, within the individual, and external, within socio-spatial fields. It represents what is taken for granted in groups, institutions and society which becomes internalised producing taken for granted notions within the individual. Doxa thus anchors the structure of a field and thus supersedes individual habitus. The crucial issue which Atkinson's critique exposes is the problematic way Bourdieu's thinking tools can be used within empirical research and the theoretical errors which can be made if a researcher thinks primarily, or solely, with one thinking tool in isolation from the rest of the toolkit.

Habitus and its relationship to the rest of the Toolkit

Habitus is only one concept within the theoretical framework Bourdieu developed in his attempts to explain 'practice': socially pattered action. The researcher must always bear in mind Bourdieu's formula [(habitus) (capital)] + field = practice; each of these concepts are required and vital within Bourdieu's theoretical framework. Their interconnected relationship is visualised in Figure 2.1. It is therefore important to elucidate further key concepts; capital, field doxa and symbolic violence.

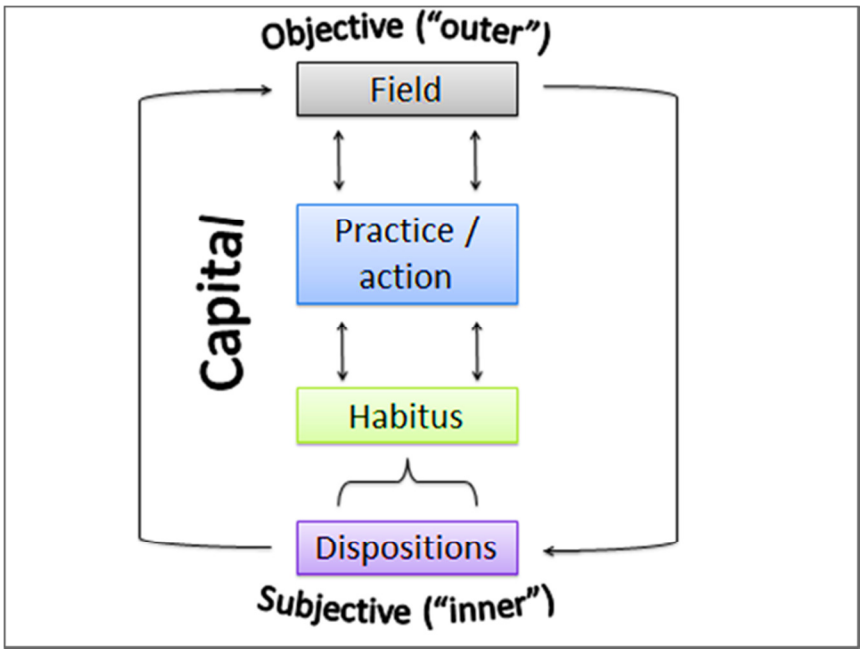


Figure 2.1: The Relationships within Bourdieu's Theoretical Tool Kit.

2.3.2: Capital

Bourdieu believed we cannot understand the social world unless we recognize the function of '*capital in all its forms and not solely the one form recognised by economic theory* (Bourdieu, 1997 [1986]: 422). According to Bourdieu we must acknowledge the

role of economic, cultural, social and symbolic capital. Economic capital can be defined as accumulation and command over money and assets. All other forms of capital are rooted in economic capital as they can, under certain conditions, be converted into economic capital and vice versa (Bourdieu, 1997 [1986]).

Social Capital

Bourdieu stated the definition of social capital[7] as:

> *"the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition"* (Bourdieu 1997 [1986]: 248).

These networks have a *value* which depends on the number of connections that can be mobilised and the volume of capital (social, cultural and economic) held by these connections. The benefits gained from social capital can be via membership within a family or other institution. Therefore, social capital can be exploited; some individuals can use their social capital to further careers (Field, 2007). However, others who rely solely on educational qualifications can be susceptible to '*credential deflation'* (Field, 2007:17) if they lack such social connections.

[7] Bourdieu is not the only academic to utilise the term 'social capital' which his work. There are another two key social capital theorists commonly cited; Robert Putnam and James Coleman. There is no room to discuss these theorists here and as such a short discussion of their conceptualisations of the term has been provided in Appendix 2.

Within *The Forms of Capital* Bourdieu talks of social capital as 'collectively-owned', realised through reciprocity and trust creating institutionalised relationships (Bourdieu, 1997 [1986]). This should not lead one to view social capital as a solely communal concept; Bourdieu's work is based on *relational thinking* particularly on the way the social agent and their external environment interact and mutually produce practice enabling both the reproduction of certain aspects of social structure and also alterations within this structure over time. Bourdieu's definition was later altered to the following lesser quoted definition:

> "*… social capital is the sum of resources, actual or virtual, that accrue to an* ***individual or a group*** *by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition"* (Bourdieu & Wacquant 1992: 503 – [emphasis added]).

Therefore, social capital can be both an individual and a group asset. These networks should not be thought of as a given, as Bourdieu states:

> *"...the reproduction of social capital presupposes an unceasing effort of sociability, a continuous series of exchanges in which recognition is endlessly affirmed and reaffirmed"* (Bourdieu 1997 [1986]: 250).

To maintain connections, time and energy must be spent, but this expenditure will only be profitable if invested with a '*specific competence*' (Bourdieu 1997 [1986]: 250): knowledge of these relationships and skill at using them. The following excerpt from *Le capital social: Notes provisoires* elaborates these ideas further:

> *"[t]he existence of a network of connections is not a natural given, or even a 'social datum', made once and for all by an act of social institution… but the product of the work of establishment and maintenance which is necessary to produce and reproduce those durable and useful bonds that are appropriate for acquiring material or symbolic profits*" (Bourdieu 1980 [cited in Robbins 2000: 37]).

Bourdieu's social capital represents networks, it can accumulate to individuals and/ or groups, yet it must be reproduced by '*an unceasing effort of sociability*' and is therefore the '*product of accumulated labour*' (Field, 2007: 18). Put simply labour + time = capital. It is inter-connected with other forms of capital – cultural, economic and symbolic – and as such can, to a greater or lesser extent, reproduce its impact within the social strata, and therefore can perpetually reproduce inequalities. Yet, social capital alone will not automatically prove resourceful without interplay with other forms of capital and, in turn, money (economic) and educational achievement or professional status (cultural) without the resource of social capital can also prove of limited consequence. This links social capital back to class or group membership. Bourdieu's discussion of social relations rests on the concept of homophily or homophilous networks (Bottero, 2009). Individuals, according to Bourdieu, are inclined to associate with others with whom they share commonalities and similarities; those from the same class background or those whom share a similar interest or hobby. This enables classes and groups to perpetuate themselves by congregating and sharing resources through the *unceasing effort of sociability* and the reciprocity this requires. Of course the incestuous nature of these networks also excludes those who are

dissimilar and thus can perpetuate inequalities and class or power based social hierarchies. In this sense social capital can be viewed as an aspect of cultural capital as opposed to a distinct capital itself (Robbins, 2000).

It has been argued that social capital is the least theoretically developed form of capital presented within Bourdieu's work (Erickson, 1996; Field, 2003). This is a fair criticism; while Bourdieu does discuss the social relations underpinning social capital this discussion is somewhat sparse and perhaps not given as much consideration as it should (Bottero 2009). This is problematic, as Bottero states:

> "*… by stressing the relational properties of social position, Bourdieu sometimes places an undue reliance on homologies between structurally equivalent positions to explain social action, without sufficiently attending to the substance of those social positions"* (2009: 403).

Bourdieu does not fully account for the potential differences within what appear to be similarities. For example, just because individuals share a class background does not remove other differences of gender, age, ethnicity, and of course the embodied experiences of each individual, which as discussed above, will always differ. A further problematic issue is that by placing emphasis on the homophilous nature of social interaction suggests that social groups are isolated which would make social change difficult. Thus Bourdieu could, again, be accused of being a determinist. The charge of determinism is discussed later. This highlights social capital as a concept which perhaps requires some expansion and adaption when utilised in the exploration of empirical data.

Cultural and Physical Capital

Cultural capital is of great importance and can be seen as one's collection of knowledge experience and values, which exists in three forms:

1) Embodied by the '*long-lasting dispositions of the mind and body*' (Bourdieu, 1997 [1986]: 243). This internal aspect of cultural capital will differ depending on the *'domestic transition of cultural capital'* (*ibid*). Embodied cultural capital is inherited or acquired through sociability within particular cultural surroundings as such external wealth can be '*converted into an integral part of the person'* (*ibid*).
2) Objectified by material objects (e.g. books, paintings). These cultural goods are an external realisation of embodied cultural capital: they presuppose economic capital and *symbolically* project one's embodied cultural capital.
3) In the institutionalised state. An academic qualification, for example, can be seen as an acknowledgment of cultural capital: a '*certificate of cultural competence*' (Bourdieu, 1997 [1986]: 244-248) which can be exchanged for monetary value in the labour market.

Bourdieu stresses that these long-lasting dispositions (embodied cultural capital) are unique to the individual and *'cannot be accumulated beyond the appropriating capabilities of an individual agent; it declines and dies with its bearer*' (Bourdieu, 1997 [1986]: 245). Incorporated cultural capital is thus almost *'indistinguishable'* from the habitus (Robbins, 2000: 34). Cultural capital is a symbolic and materially active capital which is only effective when it is appropriated and invested as a tool by the agent within particular '*fields of cultural production (the artistic filed, the scientific field etc.)*

and beyond them, in the field of social-class struggles' (Bourdieu, 1997 [1986]:247). An individual's accumulation of cultural capital is a life-long process; one's cultural capital will likely be far greater at the age of 45 than it is at 25. Cultural capital can thus be crucial to an individual's success in life.

The value of our money and assets can be utilised or exchanged in order for us to progress within the economic system. Cultural capital works in a similar manner as Robbins explains:

> *"…our social positions are only modified by our cultural tastes in as much as the cultural system assigns more value to some tastes than to others. We are not intrinsically altered by preferring Mozart over Morrissey… but the judgments of value made between our preferences within the cultural system affect our position within that system and have consequences for both our economic and our social position-taking"* (2000: 32).

One's cultural tastes, therefore, have value which can be utilised to improve one's place within the social strata. Crucially the value of any capital is reliant, to a degree on recognition by others; individuals, groups and institutions occupying positions within the fields one occupies.

Capital is '*unequally distributed and unequally available*' (Pinto, 1999: 105) and unlike economic capital which can be gained instantaneously (winning the lottery, inheriting money from a relative) embodied cultural capital requires time and labour. One's

position within the social strata can aid or hinder one's accumulation of cultural capital. Childhood is a time of great exposure to the knowledge and values of the family one happens to exist within, and by extension the values of the social class to which one belongs. A parent's 'stock' of capital will typically be passed down. Therefore, more resource rich families can provide their offspring with a stronger foundation upon which to continue accumulating capital, enabling more effective strategies for position taking. The educational system, working in conjunction with the cultural milieu of the home, assists a child in taking cultural experience and academic capability and converting it into cultural capital (Lareau, 1987). Furthermore, a child will have access to higher or lower quality of education depending on where a child resides geographically and the economic capital within the family. As such the educational system can reinforce domination and legitimisation of culturally and economically richer societal groups. However, it must be stressed that cultural capital is not a proxy for social class; an individual can be culturally inept yet, manoeuvre with relative ease within the upper middle class, perhaps due to their accumulation of other capitals, while another individual, who has been born and bred within a working class area, can have stocks of cultural capital but lack '*specific competence'* (Bourdieu, 1997 [1986]: 250) at utilising this capital for personal advancement, or lack the social connections required to effectively use this cultural capital.

While incorporated cultural capital is limited to an individual, it '*lives and dies with its bearer*', objectivised cultural capital has a life beyond individuals. The accumulation of cultural goods, works of art for example, can be passed on to the next generation. With its cultural market value such goods can be exchanged for economic capital or in turn lose their cultural value, thus economic value and '*crash*' (Robbins, 2000:35).

Cultural goods can be used to reproduce the standards of taste and enable those who accumulate these goods to physically project their tastes, distinguishing themselves from others and from vulgarity, or the low brow (Bourdieu, 1984).

In more recent years the '*omnivore thesis'* has been put forward (Peterson & Simkus, 1992). This thesis recognises the breadth of cultural tastes arguing that, in Western societies, there is a section of society which indulges in a '*greater variety of forms of culture*' (Warde, Wright & Gayo-Cal, 2007: 143) than this group would have done in the past. The cultural omnivore is able to appreciate, or is at least open to trying, a mixture of high, middle and low brow cultural goods and activities. Studies examining the cultural omnivore typically find these flexible cultural consumers to young, well educated, with middle to high income (Sullivan & Katz-Gerro, 2007). The creation of a 'pick and mix' approach to cultural goods could be due to a number of changes within Western societies over the past few decades. For example, the educational system in the UK is still polarised with '*sink*' or '*ghetto*' schools for the '*under-class'* at one end and expensive private elite schools catering for the higher classes at the other (Hill, Greaves & Maisuria, 2009: 76). However, working class access to further education has increased, enabling working class dispositions to enter the establishment and for those with working class backgrounds to acquire institutionalised cultural capital (in the form of a degree) and therefore provide them with more robust strategies for manoeuvring within cultural fields which would have previously been closed. These 'successful' individuals with habituses formed within a working class milieu can bring new ideas into these fields which, perhaps, enabled the breaking down of closed elitist tastes within these fields, exposing other agents to 'low-brow' culture. There is also the

element of technological advancements enabling increased access to diverse cultural goods and activities.

Physical Capital

Physical capital relates back to the concept of bodily hexis due to its focus on the body itself. In fact the concepts of physical capital and bodily hexis can become conflated within the literature[8]. It is therefore worth noting that what distinguishes the two concepts is the matter of symbolic value and legitimacy. The bodily hexis is directly related to a person's habitus as the *'durable and transposable systems of schemata of perception, appreciation and action'* and is revealed in '*the institution of the social in the body*' (Bourdieu & Wacquant, 1992: 127). Bodily hexis develops in conjunction with habitus and is thus, in part, the product of social location: just as one can talk broadly about a class habitus, bodily hexis speaks to class. As Shilling explains:

> *"[t]he body is also related to Bourdieu's notion of taste. 'Taste' refers to the processes whereby individuals appropriate as voluntary choices, life-styles rooted in material constraints. Taste is materialised within the body, serves to neutralise and perpetuate the different relationships that the social classes have towards their bodies*…" (1991: 655).

This issue of taste is what relates bodily hexis to physical capital due to the link to distinction, value and legitimacy. As Wacquant explains a capital is:

[8] For example Chris Shilling's 1991 article *Educating the Body: Physical Capital and the Production of Social Inequalities* appears to do this or at least fails to acknowledge bodily hexis in the introductory discussion, which is in fact, without knowing it, a great outline of bodily hexis.

> "*… any resource effective in a structured arena of social action (field) that allows one to obtain specific profits that arise out of activity and contest within that arena*" (1998: 26).

Physical capital, like all other forms of capital, depends upon value in context and can enable the bearer of that capital to gain '*specific profits'*. For a sports person, or indeed a film star, physical capital can be explicitly valuable because the body, within the fields such individuals manoeuvre, is of great consequence. The role of physical capital is thus often considered with studies on sport, for example Wainwright, Williams and Turner's study on ballet (2006), Wacquant's ethnographic work on boxing (1989, 1991) or Few and McGillivray's (2005) study of aesthetics and the 'quest' for physical capital via health and fitness clubs. Each of these studies exposes the role of the body as capital within particular socio-spatial fields but also the role the wider cultural milieu and those specific socio-spatial fields play in shaping and constraining bodies as Few and McGillivray note regarding their findings:

> *"[w]ith external medical and media discourses exerting persistent pressure on the embodied state, desire for physical capital produces a self-legitimating and regulatory regime perpetrated upon the self within the internal environment of the health and fitness club"* (2004: 161).

Yet bodies can be of great consequence to all individuals regardless of sport or celebrity. The notion of physical capital and bodily hexis expose the heart of Bourdieusian theory: the process of embodiment and the role of the body in the (re)production of power. Bourdieu's theoretical framework '*has at its very centre a*

concern with the body as a bearer of symbolic value' (Shilling, 2003: 111). Bodies are (re)produced socially, educated in ways which are perceived to be of value within particular social-spatial fields creating a *'competence of the body"* (Crossley, 2001: 106).

It is through existing hegemonic structures and hierarchical social positioning, that the behaviours, attitudes and bodily deportments of individuals are shaped. Therefore, within Bourdieusian theory the body is viewed as a '*bearer of value*' (Edwards & Imrie, 2003: 240) within society:

> "*… there is an interrelationship between the development of the body and people's social location… the management of the body [is] central to the acquisition of status and distinction*" (Shilling, 2003: 111).

Bodies can divulge much about individuals: the manner in which individuals dress, carry themselves and generally conduct their bodies within social spaces provide those around them with clues as to their status and value within socio-spatial fields. Bodies therefore contain physical capital but are also objects of *symbolic capital* as they can quickly reveal the individual's legitimacy and position. Bodies in this sense are enablers and disablers depending on their competence. Within the context of the current study, disabilities and impairments caused by the event of a stroke have the potential to threaten this competence by disrupting the bodily hexis. This could in turn see the value of a stroke survivor's body diminish or increase depending on the relationship between them and the socio-spatial fields they have historically and currently manoeuvre within.

Symbolic Capital

Symbolic capital is similar to objectified and institutionalised cultural capital in that it represents honour and prestige (Jenkins, 2002). According to Bourdieu and Wacquant symbolic capital is:

> *"...the form that one or another of these species [of capital] takes when it is grasped through categories of perception that recognize its specific logic or, if you prefer, misrecognize the arbitrariness of its possession and accumulation"* (1992: 119).

Symbolic capital is a '*transubstantiated*' (Moore, 2010: 103) form of economic capital; yet symbolic capital operates to deny this economic underpinning due to its apparent fundamental worth. It is embedded within the cultural schema. For example works of art, or what is deemed to be a work of art by those positioned to categorise items as such, (objectified cultural capital) are expensive, *priceless*, but in fact priced to an exclusionary level. However, works of art are perceived to embody an intrinsic value *as* works of art and in turn can legitimise the position of the art critic who is deemed to understand this intrinsic value. By aligning culture with capital Bourdieu has coupled the '*sacred with the profane'* (Moore, 2010: 104) and exposed the subtle workings of symbolic value. Furthermore, as alluded to above, considering the role of physical capital and bodily hexis within Bourdieu's theoretical framework the body is also a sight of symbolic value within fields and may be perceived of as either legitimate or illegitimate. Disabled bodies in this sense are at risk of being perceived as illegitimate or of little value within certain fields due to the insidious and pervasive negative stereotyping of disabled people as discussed within the previous chapter.

2.3.3: Field, Practical logic, Doxa and the Illusio

Bourdieu's concept of field and habitus are greatly interlocked. The function of the habitus depends on social space and thus practices are subject to what is occurring within the field an agent is located in (Jenkins, 2002). Within a socio-spatial field are positions which social agents (or institutions) occupy (Thompson, 2010). The social agent's position in a socio-spatial field depends upon the particular rules of the field in question working in conjunction with the social agent's habitus, enabling a 'feel for the game' within that field, and the amount of *capital* held by the agent. A field is thus hierarchical and competitive with agents entering on an unequal playing field. Agents must use strategies to gain and maintain their position and a social agent's ability to do this depends on that agent's accumulation of capital and the value of that capital is contextual, depending on the field (Thompson, 2010; Robbins 2000). Each field has its own history and set of rules which influence the strategies that can be deployed for position taking. However, much like the habitus, fields are not static and therefore position-taking is '*not simply by reference to a static network of relations*' but a process which '*accommodates both the past and the future*' (Robbins, 2000: 30).

Each field is inter-linked with society and the wider cultural milieu in which it has been formed but is also, to a degree, autonomous from society; fields have their own rules, beliefs – their own '*logic of practice'* (Thompson, 2010: 70). According to Bourdieu the selection of action obeys '*practical logic'*; habitus selects actions which are deemed suitable to the situation and make sense to the actor whose dispositions have been formed within certain fields. Each field has a different logic of practice relating to the habitus which is '*specific and appropriate to the field*' (Jenkins, 2002: 84), '*befitting its own topology'* (Prior, 2000: 143). The position holding social agents within these fields

have a habitus which provides '*a "sense of one's place"* but also a *"sense of the place of others"* (Bourdieu 1989: 19). This is related to the concept of *doxa* or the '*taken-for-granted common sense understandings of the world and ourselves*' (Lovell, 2000: 31). If the habitus was completely fluid there would be little social stability, the doxa works like an anchor of 'cultural arbitraries'. The doxa provides a link between an objective order, or structure, and subjective understandings of 'the way things are' which makes certain classifications and values seem natural and unquestionable (Deer, 2010).

Doxa performs a few inter-related roles within Bourdieu's framework but can be understood as '*pre-reflexive intuitive knowledge shaped by experience, to unconscious inherited physical and relational predispositions*' (Deer, 2010: 120). These subconscious, stable beliefs, and values, are taken for granted, informing thoughts and ultimately practice within a specific field. While the doxa can anchor the habitus, doxa is also the '*cornerstone of any field*' (Deer, 2010: 121) as it enables external social structures to be reproduced within the field via the social agent's interaction with it, as Deer explains:

> *"[t]he mutual reinforcement between habitus and field strengthens the prevailing power of the doxa, which guides the appropriate "feel" for the game of those involved in the field via presuppositions that are contained in the doxa itself*" (2010: 121).

The social world is the '*field of power'*; a multitude of fields (and sub-fields) of varying sizes with some fields more dominant than others and all fields are ultimately dominated by the economic field. There is a homology, a similarity of form, between

an overarching social field and its corresponding sub-fields enabling social agents to operate within and between a number of fields at once (Thompson, 2010). The doxa, the taken-for-granted categories and values, of each field fails to recognise its role and relation to the field of power and thus it misrecognises its part in the production and reproduction of inequalities (Thompson, 2010).

Fields are also sites of struggle;

> "*… arenas of production and circulation and appropriation of goods, services, knowledge or status and the competitive positions held by actors in their struggle to accumulate and monopolize these different kinds of capital"* (Swartz, 1997: 117).

Agents who have accumulated the most valued form(s) of capital within their field will be in a more dominant or legitimate position than those with less. For instance, Bourdieu talks of the 'intellectual field' in which academics will struggle and complete to accumulate the most cultural capital. The established agents within the intellectual field hold legitimised knowledge endowing them with power and dominance yet this can be challenged by others, particularly 'new comers' or the younger generation entering the field who invent new systems of knowledge (Swartz, 1997). Therefore, while the field is hierarchical and anchored by the doxa there is *still room for agency* and change and new movements to form within these fields. So while an agent's habitus is both maintained and altered through its interaction with fields, the fields are themselves maintained and altered by interaction with the habituses of those who compete and manoeuvre within them. Furthermore, events occurring within

neighbouring fields and events out with a particular field (for example technological advancements changing working patterns enabling flexibility) can produce change within that particular field (Thompson, 2010). The essence of field(s) rests in relationships between the positions that agents hold as Bourdieu and Wacquant state: *'[t]o think in terms of field is to think relationally'* (1992: 96). However, this does not fully explain *why* individuals continue to compete within varying social fields for species of capital, status and distinction. This is something which Bourdieu tackles with the concepts of the *illusio* (and *conatus*).

The Illusio

Why do individuals engage in work, in hobbies or intellectual endeavours, why do individuals 'play' these 'social games'? Participation within 'the game' is captured in Bourdieu's concept of the illusio;

> *Illusio is in the fact of being interested in the game, of taking the game seriously. Illusio is the fact of being caught up in and by the game, of believing the game is "worth the candle," or, more simply, that playing is worth the effort. In fact, the word interest initially meant very precisely what I include under the notion of illusio, that is, the fact of attributing importance to a social game, the fact that what happens matters to those who are engaged in it… Interest is to "be there", to participate, to admit that the game is worth playing and that the stakes created in and through the fact of playing are worth pursuing … games which matter to you are important and interesting because they have been imposed and introduced*

> *in your mind, in your body, in a form called the feel for the game* (Bourdieu 1998a, 76-77).

If an individual's habitus is structured to correspond with the structures of the field(s) in which that individual plays the game, the question of whether the game is 'worth the candle' will go unconsidered. The illusio is to be enthralled by the game. However, with interest also comes the possibility of disinterestedness and indifference. For example, Bourdieu discusses '*well-constituted societies of honor*' where '*the habitus-field relationship is such that, in the form of spontaneity or passion, in the mode of "it is stronger than me", disinterested acts can be carried out*' (1998: 87). Therefore, an individual *'can be interested in a game (in the sense of not indifferent), while at the same time being disinterested*" (1998: 77). The indifferent person, however, '*does not see why they are playing,' it's all the same to them; they are in the position of Buridan's ass*[9]*, not making a distinction*' (*ibid*). As such if the structures of the game are *not* embodied within an individual's habitus, inoculated within the body, the game may seem futile. In this sense the illusio is the oil in the machine, the fuel that makes individual's engage in acts and 'games' which appear to give their lives meaning.

Perhaps a useful addition to Bourdieu's discussion of the illusio would be the concept of the *absurd*. The absurd is *born out of this confrontation between the human need and the unreasonable silence of the world* (Camus, 1991: 28): an individual's basic hope to find meaning and purpose in their existence typically fails because the material and social world will always be ultimately indifferent towards him or her. Realisation of the

[9] The paradox of freewill in which choice can lead to a lack of ability to choose, a state of indecision

absurdity of existence could also lead to disinterest or dissatisfaction because, in the words of Albert Camus:

> *"[l]iving the absurd… means a total lack of hope (which is not the same as despair), a permanent reflection (which is not the same as renunciation), and a conscious dissatisfaction (which is not the same as juvenile anxiety)"* (1991: 23).

Without addition of the absurd there is a gap: if individuals either live the illusio or are disinterested or indifferent what about those who are confronted with the *truth* of the 'social illusion' yet continue play the game? Such individual's would be neither disinterested nor indifferent. If we introduce the notion of the absurd we can account for the *dissatisfied* and, if we allow room for philosophical concern, there is, perhaps, a possibility for the dissatisfied to become satisfied (yet not indifferent) without falling for the illusio. Adding the absurd could perhaps provide greater allowance for agency, something which Bourdieu is often accused of not giving enough credence to.

2.3.4: Doxa, Orthodoxy and Heterodoxy

The concept of doxa requires further consideration as it is at the heart of social struggle. Doxa results in the social order being perceived as legitimate though the perception of it as natural or as 'common sense'. Doxa is therefore not discussed or challenged it is the '*universe of the undisputed*' (Bourdieu, 1977: 165). It is thus through the doxa individuals come to `know their place'. Preserving the taken-for-

granted nature of a field, protecting the state of doxa, is what enables the dominant to maintain their position without contention. As Bourdieu explains:

> *"...the dominated … have an interest in pushing back the limits of doxa and exposing the arbitrariness of the taken for granted; the dominant … have an interest in defending the integrity of doxa"* (1994: 164)

The state of 'orthodoxy' however is positioned between doxa and reflexivity '*wherein the arbitrary terms of the field are consciously espoused*' (Myles, 2004: 100): the arbitrariness of the doxa is recognised but accepted. If the dominant classes cannot defend the doxa, a state of orthodoxy is their next best option. Here the nature of the field is discussed however within this discussion are 'official' / 'right' / 'moral' opinions and 'unofficial' / 'wrong' / 'immoral' opinions. As such '*[o]rthodoxy…aims, without ever entirely succeeding, at restoring the primal state of innocence of doxa*' (Bourdieu, 1994: 165). Despite the presence of discussion in the state of orthodoxy, the dominant can claim their opinion and position to be legitimate while the views and challenges expressed by the dominated are considered illegitimate. According to Bourdieu:

> *"[t]he truth of doxa is only ever fully revealed when negatively constituted by the constitution of a field of opinion, the locus of the confrontation of competing discourses"* (1977: 168).

An acknowledgement and challenge to the truth of the doxa is only fully possible in a state of heterodoxy: a situation of more or less equally competing possibilities regarding the way things could or should be. A useful visualisation of the role of doxa, orthodoxy and heterodoxy in discourse on the state of a field has been provided below in Figure 2.2. [10]

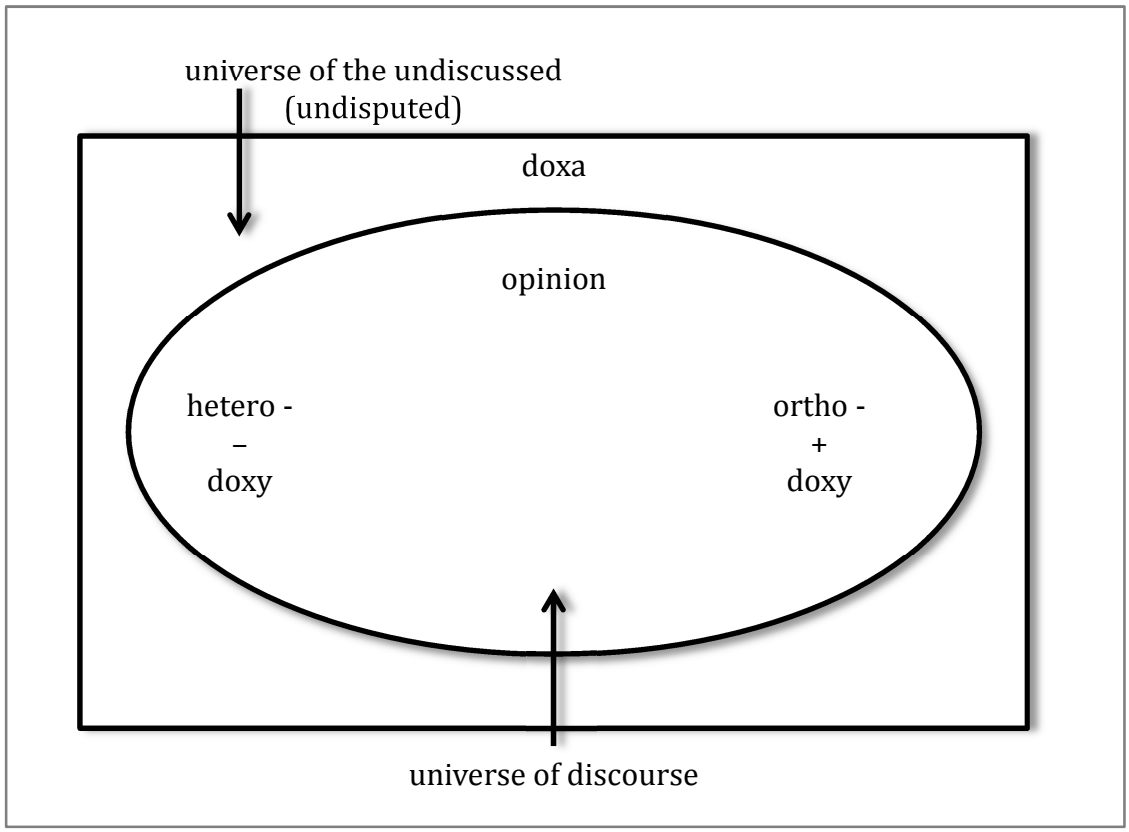


Figure 2.2: Doxa, Orthodoxy and Heterodoxy and Discourse

2.3.5: Symbolic Violence

The final key concept worth defining is symbolic violence: indirect cultural mechanisms which enable the production of social domination and restraint (Jenkins, 2002). These mechanisms are imposed on a dominated group in a way which is perceived by the dominated as legitimate, through the process of misrecognition (Bourdieu &

[10] Copied from Bourdieu (1994) *Structures, Habitus, Power: Basis for a Theory of Symbolic Power* in Dirks, Eley, & Ortner (eds.) *Culture/power/history: A Reader in Contemporary Social Theory*

Wacquant, 1992). Such acts are often subtle and small. For example, within the 'field of consumption' our apparent consumption choices and our behaviour or practice in the act of consuming can reveal not only our financial limits but the dispositions within the habitus:

> *"… symbolic violence… can be seen even in seemingly trivial practices, such as might occur when an "uncultivated" petit-bourgeois or working-class diner sits in an expensive restaurant with members of the upper class, not knowing which fork to use with the salad or which spoon to use with the soup. This imagined scenario is non-trivial… the anxiety and embarrassment that arise with the misuse of a salad fork signify and reproduce both the agent's position in an existing social structure and the legitimacy of that structure*" (Schubert 2010: 191-192).

The individual who makes this mistake highlights that they are not a member of that group or class. What makes such instances a form of violence is the experience of the individual who feels out of place or depth. Such experiences and the individual's responses to them, in the form of embarrassment or anxiety, operate to reaffirm the individual's lower status and maintain the status quo. In this sense such acts form small collective grotesqueries used to legitimise and delegitimise the behaviours of individuals. Symbolic violence thus links in with the concept of doxa due to it being accepted as legitimate:

> *"[s]ymbolic violence can only be exercised by the person who exercises it, and endured by the person who endures it, in a form which results in its misrecognition as such, in other words, which results in its recognition as legitimate"* (Bourdieu, 2002: 140).

Due to this misrecognition symbolic violence is hidden within dominant discourses and is applied both to and by the dominated: '*violence … exercised upon a social agent with his or her complicity*' (Bourdieu & Wacquant, 1992: 167).

2.3.6: A note on Criticisms

As mentioned earlier Bourdieu can be criticised for a somewhat difficult writing style. This is not the only criticism Bourdieu has been charged with. The definitions provided by Bourdieu for his key concepts can be accused of circularity and determinism. For example Harker *et al.*, in discussing capital, state:

> "...*what is capital? Capital is that which people value and (therefore) struggle for. What is strategy and struggle about? It is the activity that people engage in, in order to gain the necessary volumes of capital to achieve their aims*" (1990: 215).

This criticism is understandable; Bourdieu's concepts can appear circular and difficult to define clearly at times. Capital and habitus for instance are used extensively by

Bourdieu and, depending how they are used in empirical research, can become everything and thus nothing if these concepts are applied too liberally and without consideration of other key concepts.

Bourdieu's whole framework can appear circular if one were to break it down to the continual relationship between individuals and social space. Both influence one and another is a continual process of meaning making creating an apparent chicken-and-egg scenario. Calhoun, while persuaded by Bourdieu's explanation of social change at the individual, micro level believes that Bourdieu '*does not offer much purchase on the transformation of social systems*' (1993: 70) implying that such social systems, within Bourdieu's theoretical framework, reproduce themselves infinitely. This is, on the face of it, a fair criticism. Bourdieu was considerably concerned with highlighting and critiquing those within the dominant sections of society who maintain their social positions, not through force but through more subtle, symbolic and ultimately insidious means and therefore his early works stress the reproduction of power and dominance. Yet, Bourdieu consistently highlights that change can occur within societies but that this change will typically be a slow process the crux of which rests on the relationship between the habituses of acting individuals and fields.

The claims of a Cartesian circle are perhaps due to these critics considering Bourdieu's concepts as operating in a static state, or thinking in two dimensions. It is perhaps more appropriate to consider these concepts in a three dimensional sense as operating as a spiral as opposed to a circle. While a circle perpetually eats itself a spiral is in constant relationship with itself yet avoids consuming itself over and over. The crucial and often missed theme within Bourdieu's work is relationality; individuals and

groups can slowly produce change within fields and vice versa. In other words, Bourdieu's theory is as much one of protracted change as of reproduction as Crossley states:

> "...*innovative actions by embodied agents can both modify existing structures and generate new ones, breaking the 'circle' of reproduction … In this respect, even 'revolt' is a common feature of some fields: e.g. the artistic field, wherein successive generations reject the (surface-level) forms and criteria of their predecessors"* (2003: 44).

Jenkins (2002) and King (2000) have also criticised Bourdieu claiming that Bourdieu's theory places too much emphasis on the role of field in influencing habitus, thus practice. Like the criticism discussed above the core of this criticism rests on the most common accusation levelled against Bourdieu: determinism. David Inglis provides an unapologetic response to such claims:

> *"…the "Bourdieu is a determinist" line … is indeed the orthodox charge against Bourdieu. It is also both suspect and tedious. It is so for at least two reasons. First, and as Bourdieu was at pains to point out again and again in his later career, the phenomenological emphasis in his work on practical consciousness and reasoning involves a view of actors that sees them as creative, thoughtful, able to improvise, possessed of cunning and the ability to engage in forms of role-distance and situated reflexivity, and so on——but all within limits set by habitus and social context, especially field location… But, what completely fails to be taken on board by such critics…*

> *is that there are a whole pile of assumptions built into their own critiques of "determinism". In my view, those assumptions are liberal and left-liberal ones about the alleged creativity and thoughtfulness of all individuals… Such ideas about creativity, the dignity of the individual and the thoughtfulness of all actors are not necessarily wrong——but they are assumptions, generally never questioned, and endlessly deployed in claims like "Bourdieu is a determinist" with worrying lack of self-awareness*' (2013: 320-321).

Inglis assertions are certainly worth taking on board. The author of this thesis is politically left wing with a strong belief in social justice and personal freedom, however such left leaning tendencies do not equate to heralding agency as the most precious element of social practice. Individuals are capable of novel and creative action but to deny the pervasive role of context, social location, class, material assets, education, and individual experiences in culminating to enable such creativity is to deny the obvious and ever present reality that individuals are, bar very few exceptions, enmeshed within, and are, in part the product of, the world they exist within.

So called 'field theory' also suffers some criticism. For instance, what constitutes a field, and where does one end and another begin? The boundary of a field is where its ability to impact on practice terminates, something which could prove difficult to establish empirically, particularly in more technologically advances societies where there is an augmented ability for increased sub-fields and specialisation (Thompson, 2010; Jenkins, 2002). The boundaries of fields could also be somewhat vague. However, according to Bourdieu in order to identify and examine a given field 3 key

steps much be taken. The researcher must 1) analyse the position of the field in relation to the 'field of power', 2) map out the relations between positions occupied by agents (or institutions) within the field 3) analyse the habitus of social agents occupying positions within the field. This should allow the research to see the relationship between a social agent's position and their position taking ability (Thompson, 2010). However, with the homology of adjacent fields it could still be problematic to clearly identify boundaries, particularly as the boundaries between fields with such similarity are liable to be shifting. Field is a highly valuable thinking tool however the above criticisms levelled against it are highly problematic when attempting to apply the concept empirically, beyond those fields that can be clearly grasped such as specific fields of employment.

There are a few final worthwhile comments that should be made regarding critiques of Bourdieu's work. Social phenomena are complex, nuanced and, precisely because social action contains agency, it is not mechanistic and predictable. Therefore, as Inglis states; *we cannot reasonably expect any model of any phenomena to capture fully all the possible permutations of such phenomena* (2013: 319). Loïc Wacquant, friend, colleague and defender of Bourdieu's work has himself stated that Bourdieu's work is '*not free of contradictions, gaps, tensions and puzzlements and unresolved questions*' (Bourdieu & Wacquant, 1992: xiii-xiv). However this does not mean that Bourdieu should be disregarded. As stated towards the beginning of this chapter Bourdieu is good to think with, yet the act of thinking with Bourdieu can also require one to think '*beyond or even against Bourdieu'* (Atkinson 2010: 16) as one wades through the often murky and unpredictable waters of social phenomena. Yet, as mentioned in the preceding chapter, according to Bourdieu, theoretical concepts should be viewed as

'*polymorphic, supple and adaptive, rather than defined, calibrated and used rigidly*' (Bourdieu and & Wacquant, 1992: 23). Creativity should be at the heart of theoretical progression and advancement. An aim of this thesis was to explore the experiences and perceptions of long-term stroke survivors via Bourdieusian thinking. As such the empirical data gathered was used to explore Bourdieu's theoretical toolkit as much as this toolkit was used to explore the empirical data.

2.4: BOURDIEU'S TOOLKIT IN RESEARCH ON CHRONIC ILLNESS & DISABILITY

Bourdieu's concepts have been used fruitfully within the context of chronic conditions. For example, Dyson *et al.* (2010) have used field, capital and habitus to examine how black children with sickle cell disorder (SCD) negotiate their lives in the context of the fields of school and the clinic. This article exposes the different types of capital accumulated within the school and clinic and the alteration of the children's social standing within these two fields. The presence of SCD presents a number of challenges for the child in the context of the strict rules and routine of the classroom. Teachers do not recognise the problems faced by the child interpreting the child's actions as 'lazy' while the clinic recognises the legitimacy of behaviours associated with the condition. Kelly (2010) has explored the impact of the diagnosis of aids dementia for the individual and family exposing how such a diagnosis can shake what were once durable dispositions. According to Kelly, this resulting in a loss of the *feel for the game* requiring the sudden development of new dispositions influenced by the presence of the condition that the family were not prepared for (2010). This is a prime example of how effective Bourdieu's concepts can be for exploring the interwoven relationship between body, self and society. Utilising the concept of habitus Angus *et al.* (2005) expose the disruptive nature of home care. Often viewed as a way to maintain an

individual's sense of independence and enable them to remain in the comfort of home, this study uncovers the process whereby the increased presence of health care staff within the home environment and the delivery of healthcare within the home disrupts the 'intimate' relationship between self and home. The home thus becomes an environment interlinked with the hierarchical relations of the healthcare system impacting on the self, the habitus and the relationship between the habitus and the socio-spatial field of the home. The Bourdieusian toolkit represents an extensive and deeply interwoven set of ideas designed to enable the researcher to explore the processes of domination and the reproduction of power in a manner which accounts for the roles of structure and agency as co-creators of meaning and practice. Within this approach the body and embodiment play a crucial role making it a potentially profitable approach for examining the issues of embodiment in the context of stroke.

2.5: SUMMARY

This chapter has outlined the key thinking tools within Bourdieu's theoretical toolkit. It will be clear to the reader that this toolkit is both expansive and deeply interwoven. There could have been potential to focus strictly on habitus, capital and field without delving further into lesser used concepts such as illusio and conatus. However, such an approach would not have supplied the opportunity to truly explore Bourdieu's concepts. Furthermore, such a shallow account of Bourdieu could have put the researcher at risk of adapting and expanding upon Bourdieu's thinking tools when pre-existing thinking tools could have readily provided an explanation of phenomena.

Embedded within Bourdieu's work is the acknowledgement of the processes whereby the body becomes socialised and thus at the heart of Bourdieu's thinking is the process of embodiment. As Hughes and Paterson state:

> *"… disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning"* (2006: 101).

Studies concerned with chronic illness and disabilities must acknowledge the corporeal and the embodied subject. Acquiring a chronic illness and associated disability, or even the body-shock represented by an event such as a stroke, results in changes, not just within the physical body but also how individuals view the world via their bodies and how such individuals view their bodies within the world (Wilde, 2003; Lawrence & Kinn, 2012). This thesis is concerned with exploring the role of embodiment within the context of stroke and in order to do so Bourdieusian thinking was thus been utilised. Also noted within this chapter are the criticisms and potential limitations within Bourdieu's work therefore the research undertaken here also offered the opportunity to explore and adapt Bourdieu's thinking tools and thus expand upon the Bourdieusian toolkit.

At the time that this study commenced Bourdieusian thinking did not appear to have been utilised to explore the experiences and perceptions of stroke survivors despite the apparent fruitfulness of this approach for understanding the process of embodiment within this patient group. In order to explore whether Bourdieu's thinking

tools have been utilised to investigate the experience of stroke a systematic review was conducted. This review is presented in the following chapter.

CHAPTER 3: BOURDIEU & STROKE RESEARCH: A SYSTEMATIC REVIEW OF THE LITERATURE

3.1: INTRODUCTION

The previous sections of this thesis have outlined the context for this study; to explore the experiences of long-term stroke survivors living in the community informed by Bourdieusian thinking in both approach and analysis. The purpose of this section is to investigate whether any previous empirical research exists that explicitly examines life after stroke in relation to Bourdieu's theory or vice-versa. In order to carry out such an investigation a systematic review was conducted. In the succeeding sections of this chapter the systematic review and results are presented.

3.2: SYSTEMATIC REVIEW

A systematic review is typically designed to collect all potential data published on a specific topic area or related to a specific question and critically evaluate this data. The aim is to create a comprehensive account of what is known about the given topic area and how reliable the data on the topic is (Houser & Oman, 2010). Therefore, systematic reviews differ from more traditional reviews in that they go beyond providing a general understanding of a topic area. Systematic reviews tend to be less general and more specific than traditional, narrative literature reviews. Systematic reviews are also designed to be '*replicable, scientific and transparent*' (Tranfield, Enyer & Smart, 2003: 209) aiming to identify, appraise and synthesize all research evidence relevant to a specific question.

Within the fields of health care and medicine systematic reviews are vital for keeping track of the vast quantity of medical, nursing and allied healthcare professional publishing (Hemingway & Brereton, 2009). By identifying, appraising and synthesizing evidence researchers can make comprehensive conclusions regarding the clinical effectiveness, appropriateness, and also feasibility and meaningfulness of current and novel health care practices (*ibid*).

As with any research project or literature review, a systematic review requires a starting point; a clearly defined research question. Knowing exactly what one is looking for enables the search to be focused and avoids wasting time (Hamer & Collinson, 1999). With a question finalised it is important to consider the methods one will use. Typically search methods will involve database searching, reading through reference lists and potentially contacting researchers within the field. A precise search strategy should be outlined along with a clear protocol of exclusion and inclusion criteria and quality criteria. Once these elements are finalised the search should take place with each search logged as one proceeds. Typically a flow diagram should be kept detailing the number of studies selected and reasons for exclusion. The papers and resources used should be appraised, typically with an evidence table which can aid the synthesis of data (Houser & Oman, 2010).

3.3: REVIEW OUTLINE

A key element of this study is to use the theoretical framework of Pierre Bourdieu to explore the experiences and perceptions of stroke survivors. In order to find out

whether any previous empirical research of this kind had been conducted a systematic review was performed. It was deemed important to find out whether any empirical research on life after stroke specifically utilised Bourdieu's work in order to gage whether such an approach could claim to be novel.

3.3.1: The Research Question

The research question for this review was 'is there any published empirical research on life after stroke which *specifically* utilises Pierre Bourdieu's concepts of social capital, cultural capital or habitus?' The review question focuses on the key concepts of capital and habitus as these are the most widely utilised of Bourdieu's concepts and it is unlikely that any research which has utilised Bourdieu would not mention these concepts.

3.3.2: Inclusion & Exclusion Criteria

As part of the aim of this review was to explore whether any previous research had been published on life after stroke using Bourdieu's concepts it was appropriate to search for empirical studies only as opposed to reviews for discussion pieces. Qualitative, quantitative and mixed methods studies were to be included. Theoretical and applied studies were to be included, however, clinical or acute based studies / randomised controlled trials were not due to the need to find articles which examined the post-stroke experience. The studies were restricted to English language only, however the research could be based in any country. There were no restrictions on type of stroke under study and if the search revealed studies which included stroke survivors as a sub-group these would be considered and data used if data specific to

stroke survivors were available. Bourdieu's theoretical concepts need to have been used explicitly within the analysis and discussion or as a key aspect of the research in and of itself. Finally, Bourdieu's writings had little impact on the sociological or anthropological establishments beyond his native France until the mid-1980s, becoming popular by the 1990s. As such the search has been restricted to articles published after 1979.

Articles were excluded if they lacked empirical data, restricted to the acute or clinical setting, examined stroke risk, incidence or mortality. Articles were also excluded if there was no direct or explicit consideration of Bourdieu's concepts or if a study focused on the carer experience without exploring that of the stroke survivor. The inclusion and exclusion criteria have been listed in Table 3.1.

Table 3.1: Systematic Review: Inclusion and Exclusion Criteria

	Inclusion criteria	**Exclusion criteria**
Type of article	Empirical research published in academic journals	Review articles, discussion pieces
Type of study	Quantitative designs: cohort studies, randomised controlled trials, non-randomised controlled trials, comparative studies, case control studies Qualitative designs: any	Epidemiological / clinical studies Literature reviews Clinical guidelines Discussion/opinion papers
Population	All forms of stroke and TIA	Non-stroke Focus on spouse, family member, caregiver or healthcare professional(s)
Topic	Post-stroke, life after stroke in the community Utilising Bourdieusian theory within the analysis / discussion of data	Clinical or acute care preventative education No use of Bourdieusian theory

3.3.3: Search terms

The key search terms utilised were “stroke” OR “cerebrovascular accident” OR “cerebrovascular event” OR “cerebrovascular disease”, “health”, “social capital” OR “social networks” OR “network social capital”, “cultural capital”, “habitus” NOT “body habitus” and finally “Pierre Bourdieu” OR “Bourdieu” and were searched within title, abstract and keywords. These search terms were finalised after initial scoping searches in order to gauge those terms most likely to produce articles which met with the requirements of the review. Initially it was thought that “social class”, which is

commonly conflated with the forms of capital, could produce relevant articles however these preliminary searches revealed that this was not the case. These articles considered “socio-economic status” with no reference to Bourdieu’s concepts of social, cultural or economic capital. Mesh headings were used where possible for the term “stroke” before it was combined with “cerebrovascular accident” OR “cerebrovascular event” OR “cerebrovascular disease” in order to increase the chances of appropriate results while all other terms were Boolean/phrase searches. So called ‘SmartText searching’ was ruled out as while it produced a high number of hits the vast majority were not appropriate. For example using SmartText searching for “stroke” OR “cerebrovascular accident” OR “cerebrovascular event” OR “cerebrovascular disease” AND “cultural capital” resulted in 295 hits, on CINAHL + however none of the papers generated focused on stroke. As such SmartText searches were deemed unhelpful.

3.3.4: Databases Utilised

The databases utilised for this review were Medline, CINAHL +, ISI Web of Science, ASSIA: Applied Social Sciences Index and Abstracts and Scopus. These electronic databases enabled the search to cover both health and medical journals and social science journals. This was deemed appropriate due to the elements of the research the review aimed to find; health condition considered alongside sociological theory. The dates were limited to between the years of 1979 and 2011. The search itself was conducted in June 2011.

3.3.5: Organisation & Further Methods

Most of the databases allow for searches to be saved and re-run which enabled the steps of each database search to be easily recorded. However, searches were also logged within tables. All articles retrieved were exported to the reference management tool, Endnote X4. Once all searches were complete and references exported duplicate articles were removed from the Endnote file before titles and abstracts were examined against the exclusion and inclusion criteria. The remaining articles which required full text consideration against exclusion and inclusion criteria were then reviewed.

A single reviewer conducted the search, reviewed the abstracts and full papers due resource constraints. All studies deemed to meet the inclusion criteria were to be placed into a data extraction table categorising the study characteristics such as name of first author, year, country, type of study, and number of participants, and the key theories from Bourdieu's framework that were utilised in terms of background contextualisation, analysing or discussing the study findings. Quality appraisal was not deemed necessary as the review was designed to find out whether Bourdieu had been used within research on life following a stroke in the long-term rather than gage the quality of potentially existing research of this kind. This review aimed to see whether originality in the use of Bourdieu could be claimed.

3.4: RESULTS & DISCUSSION

3.4.1: Results

The results of this review reveal that there appears to be only a minimal amount of existing research which has specifically utilised Bourdieu's theoretical framework in examining life after stroke if any. The results from each database are outlined in Table 3.2, article content is summarised in Table 3.3 and the reasons for exclusion are detailed in Table 3.4. The search results are visualised in Figure 3.1.

Table 3.2: Systematic Review Search results by database

	Web of Science	
1.	"stroke" OR "cerebrovascular accident" OR "cerebrovascular event" OR "cerebrovascular disease"	97,768
2.	1 AND "social capital" OR "social networks" OR "network social capital"	37
3.	1 AND "Cultural capital"	0
4.	1 AND Habitus NOT "body habitus"	0
5.	1 AND "Pierre Bourdieu" OR Bourdieu	2
6.	Articles added to database	39

	Medline	
1.	"stroke" OR "cerebrovascular accident" OR "cerebrovascular event" OR "cerebrovascular disease"	59,16,69
2.	1 AND "social capital" OR "social networks" OR "network social capital"	8
3.	1 AND "Cultural capital"	0
4.	1 AND Habitus NOT "body habitus"	0
5.	1 AND "Pierre Bourdieu" OR Bourdieu	0
6.	Articles added to database	8

	Scopus	
1.	"stroke" OR "cerebrovascular accident" OR "cerebrovascular event" OR "cerebrovascular disease"	40,922
2.	1 AND "social capital" OR "social networks" OR "network social capital"	4
3.	1 AND "Cultural capital"	4
4.	1 AND Habitus NOT "body habitus"	1
5.	1 AND "Pierre Bourdieu" OR Bourdieu	2
6.	Articles added to database	11

Table 3.2 Cont.

	ASSIA	
1.	"stroke" OR "cerebrovascular accident" OR "cerebrovascular event" OR "cerebrovascular disease"	3325
2.	1 AND "social capital" OR "social networks" OR "network social capital"	36
3.	1 AND "Cultural capital"	0
4.	1 AND Habitus NOT "body habitus"	0
5.	1 AND "Pierre Bourdieu" OR Bourdieu	0
6.	Articles added to database	36

	CINAHL +	
1.	"stroke" OR "cerebrovascular accident" OR "cerebrovascular event" OR "cerebrovascular disease"	22213
2.	1 AND "social capital" OR "social networks" OR "network social capital"	4
3.	1 AND "Cultural capital"	0
4.	1 AND Habitus NOT "body habitus"	0
5.	1 AND "Pierre Bourdieu" OR Bourdieu	0
6.	Articles added to database	4

Table 3.3: Systematic Review: Article content

Total number of articles in results database	97
Duplicates removed	52
Articles on quality of life	5
Articles on risk, associations, incidence or mortality	17
Articles with an emphasis on social support	8
Articles focusing on acute / clinical	4
Articles considering race, gender, age or socio-economic status	5
Articles on carers/ family members	6
Articles on knowledge of health / stroke	1
Articles on returning to work and activities	2
Articles on post-stroke depression / anxiety / distress	3
Articles on improving service	2
Articles which specifically mention social capital	2
Articles which use a communitarian definition of social capital	2
Articles which were not stroke related	6
Articles which specifically use Bourdieu's concepts	0

Table 3.4: Systematic Review: Reasons for exclusion

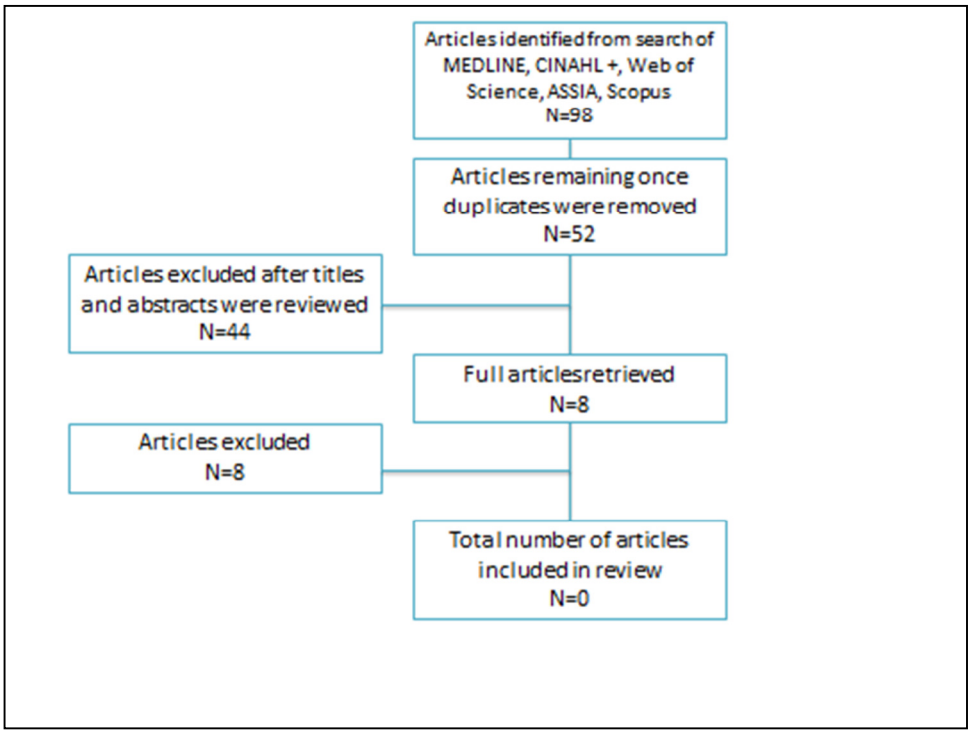
Paper	No stroke focus / improving service	Acute /risk / incidence / comparing groups	Focus of carers / family	Bourdieu not used or examined
Agewall (2004)	-	√	-	√
Agewall (1998)	-	√	-	√
Alaszewski (2007) *	-	-	-	√
Avendano (2006)	-	√	-	√
Ayerbe (2011)	-	-	-	√
Boutin-Foster (2006)	√	√	-	√
Boutin-Foster (2007)	√	√	-	√
Clinton (2004)	-	-	√	√
Colantonio (1992)	-	√	-	√
Colantonio (1993)	-	√	-	√
Costa (2010)	√	√	-	√
Crozier (2008)	√	-	-	-
DeVany (2008)	√	-	-	√
Due (1999) *	√	√	-	√
Ekwall (2005)	√	-	√	√
Fang (2009)	-	√	-	√
Garbusinski (2005)	-	√	-	√
Glasdam (2010)	-	-	√	√
Glass (1995)	√	-	-	√
Hilari (2006)	-	-	-	√
Hilari (2010) *	-	-	-	√
Hoffmann (2001)	-	√	-	√
Jackson (2004)	√	√	-	√
Kawachi (1996)	-	√	-	√
Kelleher (2004)*	-	√	-	√
Knapp (1998)	-	-	-	√
Kuhajda (2006)	-	√	-	√

Table 3.4 Continued

Lammintausta (2009)	-	√	-	√
Law (2010)	√	-	-	√
Lemic-Stojcevic (2001)	-	√	-	√
McCullagh (2005)	-	-	√	√
McNamee (1998)	√	-	-	√
Nambisan (2010)	√	-	-	√
Norris (1990)*	-	-	-	√
Orbanes (2002)	√	-	-	√
Ostir (2002)	√	-	-	√
O'Sullivan (2009)	-	-	√	√
Pih (2008)	√	-	-	√
Pound (2011)*	-	-	-	√
Robison (2009)*	-	-	-	√
Rutledge (2008)	-	√	-	√
Stephens (1987)	-	-	-	√
Stewart (2006)	-	-	√	√
Suh (2010)	-	-	-	√
Tausig (1992)	-	-	√	√
Thompson (1993) *	-	-	-	√
Tokuda (2009)	√	-	-	√
Toschke (2009)	-	√	-	√
Vitullo (1996)	-	√	-	√
Vogt (1992)	-	√	-	√
Wen (2005)	√	√	-	√
Wilcox (1996)	√	-	-	√

* Full article reviewed

Figure 3.1: Systematic Review: Flow Diagram of literature search



It is clear from the tables and figures above that the majority of articles which were generated by the search involved some consideration of social networks of social support (n=89). The two articles which did discuss social capital as opposed to social networks or social support, Kelleher *et al.* (2004) and Pound (2011), did not use Bourdieu's conceptualisation. In fact Bourdieu is neither cited nor mentioned within either article. Where the search terms "cultural capital", "habitus" NOT "body habitus" and finally "Pierre Bourdieu" OR "Bourdieu" were used very few articles (n=9) were generated. None these articles were stroke related.

3.4.2: Discussion & Limitations

The systematic review outlined above sought to find out whether any published articles which explicitly utilised a Bourdieusian approach in the exploration or

investigation of life after a stroke exist. The results of this review suggest that there is a gap within stroke research regarding the use of Bourdieusian analysis. Therefore, using Bourdieu to explore and investigate the impact of stroke on community dwelling stroke survivors was likely to be novel.

It should be noted that this review was highly focused and could be accused of being somewhat narrow in its search strategy; only published peer review articles were sought, from what could be considered a relatively narrow selection of databases. However, as this review forms only a small part of this doctoral thesis and thus the review was conducted by a single individual. Therefore, the potential scope of the review needed to be kept to a manageable size. Despite the relatively small size of this review the databases utilised cover both health services research and sociological journals which are where articles utilising Bourdieu within the context of health and illness are likely to be published. As such it is likely that this study was novel in its use of Bourdieu.

CHAPTER 4: ABSTRACT CONCERNS & METHODOLOGICAL MATTERS

4.1: INTRODUCTION

The concern of this thesis is to explore the experiences and perceptions of long-term stroke survivors living in the community, utilising the theoretical toolkit presented in the work of Bourdieu. The preceding chapters have presented stroke as a form of chronic illness and disability as well as outlining Bourdieu's key thinking tools. The aim of the current chapter and the succeeding chapter is to present the methodological approach utilised and the philosophical and practical issues which influenced this approach. This chapter focuses on explaining the issues which influenced the choice of methods and the methods chosen, while the following chapter outlines the methods in practice.

4.2: RESEARCH QUESTIONS

As outlined within the preceding chapters, stroke is a bodily event which happens to an individual, however due to acquired impairments, the impact of this event can transform how the individual interacts with the external world, alter social relationships, impact upon the individual's ability to engage in valued activities and in turn threaten an individual's sense of self. While considerable literature exists on the short term experiences of stroke survivors there is little on the longer term experiences of living with stroke in the chronic phase. What literature does exist on the long term experience reveals that stroke survivors often struggle with their condition many years post the stroke event.

The considerable physical, personal and social impacts of stroke provide a prime example of how the body, the external world, other individuals, and an individual's identity are interwoven, impacting on each other in a process of continual meaning making. In this sense the experience of living with stroke highlights the problematic process of embodiment faced by those who acquire impairments, disabilities and chronic illnesses. Bourdieusian thinking tools present a potentially fruitful theoretical approach for exploring the interwoven nature of the body, the self and society. As such these concepts could be used to great effect in the study of the experiences and perceptions of stroke survivors. Therefore, the primary research question relates directly to the research population;

(1) *What are the experiences and perceptions of those living with stroke in the long-term?*

I. *How do stroke survivors absorb the experience of stroke and associated impairments into their embodied identities?*

II. *Does this process of embodiment reconcile the pre and post-stroke self?*

III. *Do long-term stroke survivors experience on going challenges in their daily lives?*

The second question is a theoretically minded question which will be answered thinking with Bourdieusian concepts and expanding or adapting upon them depending on the data collected;

(2) *Can Bourdieusian thinking enable an in-depth understanding of the embodiment process for those living with stroke in the long-term?*

I. *Are the contents of Bourdieu's theoretical toolkit robust enough to explore and explain the experiences and perceptions of long-term stroke survivors or does it require theoretical adaption and expansion?*

The overarching research question, question 1, was intentionally broad enabling the exploration of the whole experience of living with stroke as opposed to focusing on relationships, or within the confines of a quality of life approach for example. Thus the data and the theoretical approach drove which aspects of living with stroke required scrutiny and examination. The second question was designed to provide a theoretical lens to the research process and also offer the opportunity to explore and potentially adapt Bourdieusian thinking tools.

The role of research questions is to crystallise the specific aims of research and to focus the path taken by the researcher. Research questions also help to identify the research population and provide clarity as to the most appropriate methods that can be used to investigate the phenomena under study. The development of research questions, and how phenomena should be approached and analysed, is influenced by the researchers' own personal values and beliefs and by the ontology the researcher feels is most sympathetic to their own personal worldview. The following section, *Methodological Justification*, will reflect on the personal and philosophical issues which impacted on the choice of approach taken within this thesis.

4.3: PARADIGMS & PONDERINGS

Within the kaleidoscopic field of the social sciences it is standard practice to separate research into three key types: qualitative, quantitative and 'mixed'. Qualitative and quantitative approaches are typically viewed as representing two distinct paradigms: '*belief system or worldview'* (Guba & Lincoln, 1994: 105). Despite the separation between qualitative and quantitative approaches there is a growing trend for 'mixing' both qualitative and quantitative methods, known as mixed methods research. There is no single definition of mixed methods. For some the onus of mixed methods is in the integration or triangulation of data to produce findings of both breadth and depth, while for others a design can be thought of as mixed without the data itself necessarily requiring integration (Johnson *et al.,* 2007). Following a review of various definitions of mixed methods research Johnson *et al.* have provided the following definition:

> *"… mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the purpose of breadth and depth of understanding and corroboration"* (2007: 123).

The approach used within this thesis is a mixed method design due to the use of a survey, typically associated with the quantitative paradigm, followed by the use of typically qualitative methods; interviews and a case study. The data from the survey was utilised to enable a process of purposive sampling for the core method of data collection, interviews. Data from the survey was also utilised to develop personalised interview guides and acted as an aid to the qualitative analysis. However, the two

forms of data were not intended to be fully integrated. This design is fundamentally qualitative with the use of mixed methods for data collection.

There is considerable debate surrounding mixed methods approaches due to the apparent contradictory philosophical or ontological underpinnings of qualitative and quantitative research. However, part of this controversy is based in the *methods* associated with qualitative and quantitative approaches being conflated with the ontological and epistemological assumptions which are thought to underpin qualitative and quantitative approaches. However, as will be discussed later, within the real world of research the division between these methods is, in many ways, an arbitrary one. Despite the current design being predominately qualitative in focus, as the data collection methods are mixed it is worth briefly reviewing qualitative and qualitative research and the philosophical underpinnings of each approach.

4.3.1: Qualitative & Quantitative Research

There is no room here to delve into the history, complexities and controversies within and between qualitative, quantitative and mixed methods research. Such matters are the concern of social science text books (for example Bryman, 2001, 2012; Creswell, 2003; Tashakkori & Teddie, 2009). The aim here is to provide a flavour of these issues.

The term 'qualitative research' is a broad term encompassing many different approaches such as ethnography, phenomenology, and grounded theory. Despite these categorisations all qualitative research typically holds similar aims (Atkinson,

Coffey, & Delamont, 2001); to explore the way individuals interpret the world in which they live and their experiences within it and in turn to make the social reality of people and groups understandable to those somewhat external to that, particular, reality. Quantitative research is associated with investigating phenomena using statistical techniques typically with the aim of testing a hypothesis. As such quantitative research typically investigates groups and seeks to explain the actions and behaviours of such groups through measurement as opposed to analysing speech and text and utilising reflection.

A central aspect of a qualitative approach is the notion that people construct reality as they continually interact with the world they occupy (Crotty, 1998). Inherent in this approach is the belief that multiple subjective realities exist and that these realities are in constant flux. Quantitative research however is often considered to view reality as more static, general, observable and thus measurable. The preceding sentences have touched upon the philosophical issues which are perceived as underpinning qualitative and quantitative approaches. These issues should be given further consideration as it is often the researchers own philosophical leanings which influence the questions posed and thus methods utilised within his or her research.

4.3.2: Are Qualitative & Quantitative Methods a Misconception?

Another issue which should be considered is the arbitrary relationship between paradigms and methods. Qualitative approaches typically collect data via in-depth interviews, focus groups, or participant observation. Such approaches are most suitable for capturing the subjectivities of individual experience. These methods tend to be based on interaction between the researcher and the researched and as such

qualitative studies usually involve a relatively small number of participants due to the obvious issue of time: interviews and other qualitative methods such as focus groups require time to conduct and can also take considerable time to analyse. Quantitative approaches however typically collect data in a manner that enables the data to be analysed numerically such as survey or questionnaire. In this manner it is not the individual that is of concern but the whole research population and sub-groups within that population. Key outliers within the data can be considered in more depth due to the fact that they do not conform, however outliers are also often removed as they skew the data and impact of the general conclusions that can be made. As such these methods also create distance between the researcher and the researched.

However, the belief that quantitative approaches are essentially objective and technical, while qualitative approaches are subjective and non-technical is a '*misconception*' (Gorard, 2006: 67). Such assumptions underlie the categorisation of research into distinct paradigms, yet such categorisations are not always in keeping with what actually occurs in the real world of research (Onwuegbuzie & Collins, 2007). For instance, both open-ended data (typically considered as qualitative) and close-ended data (associated with quantitative methods) if aiming to explore opinions and perceptions both represent open-ended, subjective phenomena: the response an individual provides to both interview questions and survey questions remain inherently subjective. In addition, the decisions researchers make are based on their own subjective reasoning. This remains true regardless of whether the research is based in numbers or words and visual, observational data. Data collection methods are typically open or close-ended. The placement of such methods in either the quantitative or qualitative paradigm is founded in assumptions regarding how the data

is analysed and used. It is fair to say that close-ended methods are typically quantified, while data collected in an open-ended manner are customarily grouped into themes. However this does not mean that this is how these forms of data *have* to be analysed. Data collected via open-ended methods can be quantified and close-ended data does not have to be quantified. For example, a close-ended survey could be utilised in a case study and analysed and reported without numbers being used. Therefore a close-ended/quantitative vs open-ended/qualitative distinction in research methods, which aligns methods with apparently distinct paradigms, is based on the *most common* analysis and use of the data as opposed to the potential uses of the data. This point is crucial to the use of methods within this thesis where a survey tool was utilised, not with the aim of testing a hypothesis and create generalisable conclusions, but primarily to furnish a sampling pool and enable a process of purposive sampling for the interviews.

4.3.3: Issues of Ontology & Epistemology

Qualitative approaches and quantitative approaches are often differentiated on ontological and epistemological grounds. Ontology refers to what exists: it is concerned with the nature of being or assumptions regarding what we believe social reality to be (Blaikie, 2000). Epistemology refers to knowledge, and epistemological concerns are thus based on beliefs regarding the nature of knowledge: it is one's position on how '*what is assumed to exist can be known'* (Blaikie, 2000: 8).

Researchers embarking on qualitative research are *likely* to believe multiple realities exist concurrently (Creswell, 2007). This ontology is aligned with subjectivism - the belief that social phenomena is rooted in the ideas, values and associated behaviours

of individuals - and an interpretivist-constructivist epistemology. Interpretivists maintain that individuals cannot be expected to react perfunctorily like chemicals in a laboratory due to the presence of consciousness, thoughts, feelings and awareness. Individuals interpret, and consider before deciding on the best action to take. In this sense an action is an act with *meaning*. Constructivism asserts that '*social phenomena and their meanings are continually being accomplished by social actors*' (Bryman, 2012: 33). As such qualitative research is typically the study the individual in context. The quantitative researcher, on the other hand, is often viewed as sympathizing with an objectivist ontology, which asserts that an objective reality exists, can be measured and known through collecting more complete information using a positivist epistemology. Positivism, in crude terms, is the opposite of interpretivism where actions are viewed as mechanical: individuals are removed from context and their attitudes measured, and those responses are used to make generalisations. According to Schwandt the objectivist position therefore holds:

> "…*the possibility of some kind of unmediated, direct grasp of the empirical world and that knowledge ... simply reflects or mirrors what is 'out there'"* (2007: 38).

It is typically on the grounds of ontological and epistemological distinctions that some argue the mixing of qualitative and quantitative methods is improper. However, others, such as pragmatists, place the focus onto the research question or *problem* as opposed to philosophical issues. In this context the combining of qualitative and quantitative methods is viewed as appropriate for answering a research question. Epistemological issues really come down to how data is used and what the researcher

believes can be known and stated about phenomena as a result. Within this thesis *quantified* data was used to categorise survey respondents for purposive sampling purposes as opposed to being used to state anything explicit about the population, and in the analysis stage of the research individual survey responses were used to assist the analysis of interview data and to assist the development of case profiles for the instrumental case study analysis. Individual survey questions were utilised to gain insight into the interviewee and considered thematically, linking the two data sources in a qualitative manner as opposed to *integrating* quantitative and qualitative data together. Therefore, the mixed methods debates are not of direct consequence here.

4.4: THE WORLDVIEW OF THIS THESIS

4.4.1: Sympathising with Critical Realism

It is important to reflect upon one's own worldview or ontology as ultimately this will have underpinned the type of research one is interested in and how one believes the research problem should be approached. On a personal level the author of this thesis often finds that the time spent agonising about the philosophical aspects of conducting research, while in many ways worthwhile, creates abstract problems which over complicates the often pragmatic world of real life research. It often makes more practical sense to be mindful of philosophy but not necessarily directed or indeed curtailed by it. This comes from a belief that being drawn too deeply into philosophical, abstract discussion can detract from the act of research and a belief that the 'rules' of ontology and epistemology should be considered explicitly at the beginning of a research project but not used to guide that project *religiously*. The author of this thesis is in agreement with Maxwell (2011) and Abbot (2001, 2004) who believe that epistemology and ontology should not be viewed as '*a set of premises that*

governs or justifies … research, but as resources for doing … research' (Maxwell, 2011: 13). The researcher would also wish to avoid branding herself with a particular ontology as the act of doing so can be constrictive and potentially misleading: an individual's worldview will not align directly with a socially constructed definition of a particular ontology due to the highly subjective nature of having a personal worldview. An individual's worldview is ever evolving and subtly shifting matter. This view is perhaps a reflection of the Bourdieusian thinking at the heart of this thesis.

Despite the author's apprehensions regarding proclaiming affiliation with one, particular ontology, she can admit that the philosophical perspective which she feels most *sympathetic* towards is that of critical realism. The realist perspective is typically associated with positivism. Positivism can be viewed as a form of *naïve realism* (Guba & Lincoln, 1998), a perspective which argues that the external world can be truthfully described and causally explained which in turn suggests the use of a quantitative methodological approach. Critical realism however goes some way to bridging the gap between the objective-positivist and the subjective-interpretivist as it is a:

> *"…doctrine reconciling the real, independent, objective nature of the world (realism) with a due appreciation of the mind-dependence of the sensory experiences whereby we know about it (hence critical). In critical, as opposed to naive, realism the mind knows the world only by means of a medium or vehicle of perception and thought; the problem is to give an account of the relationship between the medium and what it represents"* (Blackburn 1996: 88).

Critical realism holds that there are knowable structures however it also recognises that '*[s]ocial phenomena (like most natural phenomena) are the product of a plurality of structures'* (Bhaskar, 2010 [1989]: 2). Therefore, while positivism argues that there is a single knowable reality, and constructivist-interpretivism argues that there are multiple realities, critical realism reasons there is a knowable reality however it is only partially comprehensible and therefore there is no single correct understanding of reality. Critical realism thus allows for the mental structures, or the subjective understandings, of individuals to be recognised as playing a role in the construction of reality; society and the individual continuously produce, reproduce and amend each other. In relation to the current study it presents an ontology which is sympathetic to the theoretical aspects of the thesis as Bourdieu was himself concerned with how individuals and the external world interact with one and another in the process of meaning making.

A final issue to do with ontology and epistemology which is worth giving some consideration is that the two concepts are often conflated to be the same thing or ontology is consumed within the definition of epistemology (Maxwell, 2011). This is perhaps due to academic lethargy or a simple wish to break free from the sticky philosophical underbelly of the social sciences. Whatever the cause, this 'collapse' of the distinction between the two (Lincoln & Guba, 2000) is problematic as it makes the learning and appreciation of epistemology and ontology an unduly complicated and confused process and also because it furthers an uncomfortable and unrealistic assumption that certain ontologies can only exist alongside, or even within, certain epistemologies. This however is not the case in the real world of research. Being a realist or critical at the ontological level does not prevent one from being an

interpretivist at the epistemological level as '*our knowledge of the real world is inevitably interpretive and provisional rather than straightforwardly representational*' (Frazer & Lacey, 1993: 182).

In approaching this thesis the author has held the worldview that there are certain rules or 'games' which typically influence behaviour at the individual, group and societal level however such rules are not obeyed mechanically and are open to question and contention. Such rules also subtly change *because* they are open change due to the actions of individuals and groups. There are also an immeasurable number of such rules which influence behaviour and these are context bound; there is a reality but that reality is alterable and how that reality is perceived is subjective. However, importantly the author also believes that the subjective, values, beliefs and intentions, while not openly observable, are a part of the real world; they are a hidden yet an essential aspect of reality and therefore an attempt to understand and explain the subjective is a worthy endeavour and something which exists at the heart of this thesis.

In order to grasp a level of understanding of the subjective, methods which are most appropriate to gaining subjective data should be used. Research methods therefore, are fundamentally an issue of *appropriacy*. As qualitative data collection and analysis are most appropriate for eliciting more subjective data this was deemed the appropriate approach to use to understand the experiences and perceptions of stroke survivors.

4.4.2: Inductive & Deductive Reasoning

Connected with ontology and epistemology is the issue of reasoning. Qualitative research generally aims to achieve *verstehen* (meaningful understanding of phenomena) and also involves the exploration, elaboration or creation of theory. Thus qualitative research typically applies *inductive* ways of thinking. It could be argued that the inductive approach results in uncertainty as the researcher is using specific observations to form broader theories and conclusions. Blaxter, Hughes and Tight (2010) however, support the adoption of an inductive approach as it involves in-depth understanding of the research subject and enables the researcher to uncover and explore alternative accounts of the research problem. For generalizable conclusions a deductive approach, which starts with a theory and hypothesis and seeks observations to support or refute that hypothesis, is more appropriate. This form of reasoning is associated with quantitative approaches. However, the findings and conclusions from inductive or deductive approaches should not be viewed as more or less valid then the other if we accept that there are different forms of knowledge in the world and that knowledge is perhaps more about relevance and appropriacy than whether or not the knowledge itself is more generally legitimate and another form of knowledge.

The reasoning which has influenced this thesis has been somewhat of a mixture of both inductive and deductive reasoning in that theoretical concepts have been explored, appropriated but also expanded upon. The author of this thesis would argue that for most social scientists involved in applied research, reasoning is based neither within a strictly inductive approach nor within a deeply deductive approach. Rather our reasoning is likely to straddle these two forms of reasoning. Often within qualitative approaches the exploration of *data* is given precedence over the

exploration and expansion theoretical concerns. The data is meant to 'speak for itself' with theoretical ideas being utilised after initial analysis of data. The methodology which epitomises this highly inductive approach is grounded theory. Grounded theory offers a method for theming and categorising data, linking these categories, and utilising these connected categories in a set of theoretical propositions. A key problem with grounded theory is that it does not acknowledge existing theoretical and conceptual explanations of similar phenomena from the outset of analysis. This can limit its explanatory potential (Creswell, 1998) and can risk the development of theoretical explanations which are ultimately 'old wine in new bottles'.

An antidote to the potential pitfalls of grounded theory is Layder's adaptive theory approach (1998). Arguing from a critical realist perspective, Layder believes that empirical research without theoretical guidance should not be considered the most valid approach to qualitatively orientated research. Layder recognises that relevant theory can be known and considered before the collection of research data and argues against the grounded theory approach due to its privileging of data and, because it abandons the notion of prior conceptual schemes, it loses the advantage of building on previous social theory and wastes pre-existing knowledge.

As Layder explains adaptive theory:

> "*… centralizes the interconnections between, on the one hand, actors meanings, activities and intensions (lifeworld) and, on the other, culture, institutions, power, reproduced practices and social relations (system elements"* (1998: 27).

The aim of adaptive theory, therefore, is to recognise the links between structure and agency. Expanding upon this Layder later states:

> *"… adaptive theory stresses that to some extent social research should concern itself with investigating agency-structure linkages understood against the background of multiple social domains and to some extent be concerned with generating theory that throws light on different aspects of agency-structure and social domain linkages"* (2006: 292).

This thesis sought to utilise Bourdieu's theoretical toolkit in the exploration of the experiences and perceptions of stroke survivors due to the potential of this theoretical perspective for aiding explanation of the interwoven relationship between the body, self and society. Adaptive theory with its combination of both inductive and deductive reasoning and its recognition of the relationship between structure and agency was thus deemed a useful ***guide*** for the reasoning used in this thesis. It should be noted however that the adaptive theory approach was not used rigidly, but elements of its ideas and principles were used as a form of guidance. This enabled greater flexibility and the potential to be pragmatic.

4.5: THE METHODS USED: AN ISSUE OF APPROPRIACY

As discussed above the worldview which has influenced this thesis is sympathetic towards that of critical realism and the reasoning which has influenced analysis, adaptive theory, is one which reflects this ontology. The choice of methods has been linked to these issues but rests fundamentally on appropriacy. Before the research

process is outlined below it is important to address clearly *why* certain methods were chosen.

This thesis was concerned with gathering data on personal perspectives and experiences while actively using a theoretical perspective in the gathering and analysing of this data. Methods associated with qualitative methodologies were deemed most appropriate for the collection of this data. While structured interviews contain an order of questions deigned to be presented to interviewees in a standardised manner, the purpose of semi-structured interviews is to be flexible and accommodating of issues which occur within an interview but were not initially present within the interview guide. The interview guide acts as an aide memoire rather than a ridged set of questions. This allows the interview to be, in part, shaped by the interviewee's perspectives as well as the researcher's interests. Semi-structured in-depth interviews were thus deemed as the most appropriate method for eliciting the subjective data sought.

Interviewing is an appropriate method for gathering more subjective data. However sampling strategies, such as convenience or snowball sampling, for interviewing are potentially restrictive in that the researcher often cannot be as selective as s/he would ideally like. In the case of the current study, stroke survivors living in the community many years post stroke event were the population of concern. Accessing potential interviewees from this population presented logistical issues. The population was spread across a wide geographical area which presented time and location constraints. As the population were years post-discharge accessing individuals via facilities such as

clinics meant the interviewees would be restricted to those regularly attending such facilities. While stroke support groups could have been utilised to access potential interviewees, and a process of snowball sampling used, this would have also meant the interviewees were likely to be restricted to those who use support groups, automatically excluding those who cannot or will not utilise such groups. Utilising a postal survey greatly opened up the sampling pool as it enabled access to potential interviewees which convenience sampling or snowball sampling could not have accessed. Utilising a survey also enabled a process of purposive sampling, in which cases are selected based on characteristics thought to be of interest to the research, to be employed.

Finally this thesis was concerned with exploring and potentially expanding or adapting theoretical concepts. As such a layered approach to analysis was utilised. The first phase of the qualitative analysis involved a theoretically driven thematic analysis designed to explore the data in relation to Bourdieusian thinking tools broadly and thus highlight broad themes. A second focus thematic analysis was then employed to mine salient themes. Following this an instrumental case study analysis was deemed an appropriate method to enable a deeper exploration into key aspects of the data and allow an opportunity to adapt Bourdieusian thinking tools. Yin has defined a case study as:

> *"... an empirical enquiry that investigates a contemporary phenomena within its real life context especially when the boundaries between phenomenon and context are not clearly evident"* (1994: 13).

Stake (1995) however, has outlined both intrinsic case study and the instrumental case study approaches. The intrinsic case study approach is concerned with the '*particularity and ordinariness'* of the case rather than understanding '*some abstract concept or generic phenomena'* (1995: 237). Within an instrumental study, however, the *'case is of secondary interest; it plays a supportive role, facilitating our understanding of something else*' (*ibid*). In an instrumental case study the researcher is concerned with deepening understanding of an issue or expanding and refining a theory. Stake has also outlined a collective case study approach which refers to analysing a set of case studies similar to Yin's multiple case studies (Yin, 1994). Studying more than one case enables comparisons to be made in order to investigate similarities and differences and multiple cases can produce a more substantial argument for the testing, expansion or adaption of theory. Within the current study the purpose of the case study was to expand upon the theoretical themes emerging from the interview data therefore two interviewees who exemplified two key theoretical themes were selected and examined in-depth in order to build an explanation of these themes and expand upon the theoretical concepts used. This case study approach was labelled an instrumental multiple case study due to its focus on theory and use of more than one case.

4.6: SUMMARY

To summarise the issues discussed above, the approach taken within this thesis has been based on practical and philosophical grounds. The methods used were chosen on the grounds of appropriacy and with a worldview which recognises that reality is complex, shifting and only knowable in part and imperfectly with the internal and external being interwoven. A survey enabled access to a geographically spread out population, and allowed for purposive sampling to be conducted while interview data provided the opportunity to gather subjective data and a case study phase facilitated a process of theoretical exploration and expansion. Underpinning the analysis were the principles of adaptive theory which allowed for theoretical concerns to play a key role in analysis.

CHAPTER 5: METHODS IN PRACTICE

5.1: INTRODUCTION

The purpose of this chapter is to outline the methods taken forward within this thesis. The research population and setting will be outlined first before the process of developing data collection methods is discussed. The last two sections are concerned with detailing the sampling and recruitment process for each aspect of the study and the process of data analysis.

5.2: RESEARCH POPULATION & SETTING

The population of concern to this thesis were community dwelling stroke survivors living in the chronic phase of their condition. The research was based at The University of Dundee with links to the stroke team at the University's teaching hospital, Ninewells Hospital in Dundee. Therefore, the most practical population to recruit from were stroke survivors living within the catchment area of Ninewells Hospital. This catchment area covers a large geographical area encompassing the Tayside region and North East Fife (Figure 5.1).

Tayside is currently split into three local authority areas: Dundee City, Angus, and Perth and Kinross. However, the local health board governs Tayside as a whole. Tayside is a far larger geographical area than NE Fife with an estimated population of 399,550 by the year 2009 according to the 2001 census. Approximately 145,910 persons reside within Perth and Kinross, 143,390 in Dundee City and a further 110,250 in Angus. NE Fife has a comparably small population of 74,357 persons. While death rates from stroke in Angus are similar to the Scottish population as a whole they are 17% higher

than rates in Dundee City and 12% higher than Perth and Kinross (Directorate of Change and Innovation 2004).

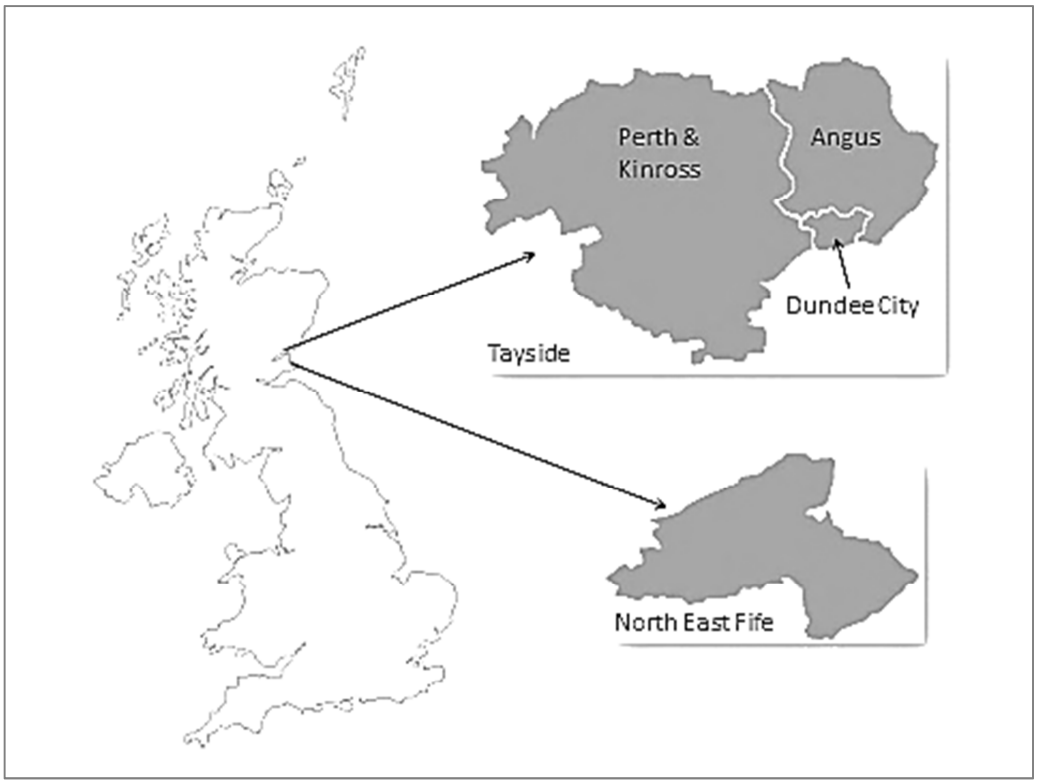


Figure 5.1: Geographical area of recruitment for the postal survey

5.3: DATA COLLECTION METHODS

5.3.1: Development of the Postal Survey

This thesis sought to explore the experiences and perceptions of stroke survivors and was guided by theoretical concerns. Therefore, beyond demographic questions the survey needed to gather data on physical function, cognition and communication as well as data that could provide insight into Bourdieusian theory. It is known that stroke can impact upon well-being or health related quality of life (HRQoL) (Hackett *et al.,* 2000; Tengs, Yu & Luistro, 2001; Abubakar & Isezuo, 2012). HRQoL was deemed a useful aid to identify those who may or may not be living well with their condition.

There are a plethora of pre-existing scales which assess function, well-being and HRQoL. Rather than create something novel in order to gain insight into respondents function and well-being it was deemed more appropriate to utilise something pre-existing validated with a population of stroke survivors. Therefore, a suitable physical function scale and HRQoL scale needed to be identified alongside the development of demographic questions and questions to elicit information relevant to Bourdieusian theory.

Health Related Quality of Life and Function

The purpose of the function scale and HRQoL scale was to simplify the sampling process for the interview phase by enabling potential interviewees to be classified. The individual questions within these scales were as important as the scale overall as the individual questions were to be used to aid the analysis of interview data as part of the thematic analysis and the case study analysis. However, while this thesis was not concerned with utilising the survey data for strictly quantitative concerns the validity, reliability and *suitability* of the scales chosen were still worth considering. This data could be utilised in future studies and as such it was deemed appropriate to select validated scales which were most suitable to their population and would provide useful data. Consequently, validated and reliable scales which had been designed for, and tested with, a population of stroke survivors were sought.

The Burden of Stroke Scale

There are an increasing number of stroke-specific quality of life measurements: the *Stroke Adapted Sickness Impact Profile* (SA-SIP) (van Straten *et al*., 1997), *Stroke*

Specific Quality of Life Scale (SS-QoL) (Williams *et al*., 1999), and *The Burden of Stroke Scale* (BOSS) (Doyle *et al.,* 2004) to name a few. These tools are designed to deal with factors most salient for stroke survivors and can thus get at more *relevant* data than HRQoL scales which are not condition specific. In recent years stroke-specific HRQoL scales have been produced which also measure the impact of communication impairment on quality of life such as the *Stroke and Aphasia Quality of Life Scale* (SAQoL) (Hilari *et al*., 2003). The BOSS also contains a sub-scale on communication impairment. The SAQoL and the BOSS were considered for these reasons. Both have been shown to be valid for use on the stroke population (Hilari *et al.,* 2003; Doyle *et al.,* 2004, 2006, and 2007). Both are also rather lengthy; the BOSS contains 64 items and the SAQoL 39. The shorter length of the SAQoL is attractive for a postal survey such as the one used within the current study. However the longer scale, the BOSS, has other advantages; it is conceptually based in the World Health Organisation's *International Classification of Functioning, Disability and Health* (ICF) which has been proven as a robust marker of the content of HRQoL scales (Geyh *et al.,* 2007; Cieza & Stucki, 2005). The ICF is a classification of health and health-related domains including physical, individual and societal perspectives. The ICF views disability and function through three perspectives of the body, activity and participation. The ICF is therefore designed to consider disablement beyond physical impairment (internal) to include social and environmental (external) disablers, and as such reflects the lived experience of disability. In utilising this approach, Doyle *et al.* have worked from the assumption that:

> *"… patient appraisals of functioning may be independent of their appraisals of well-being; that appraisals of well-being, like functioning, may be domain-specific; and that such judgments may be influenced by the extent to which functional limitations interfere with valued life activities"* (2004: 998).

As exploring the experiences and perceptions of stroke survivors and the process of embodiment represent crucial concerns of this thesis the conceptual basis of the BOSS was particularly appealing. As such the BOSS was deemed in keeping with the study due to this emphasis on the individual context as well as the impact of external social structures. The scale contains short sub-scales on communication and cognition which enabled these issues to be considered as part of the purposive sampling process. Patrick Doyle and his team were contacted and provided a version of the scale in postal format for use within this study (the BOSS can be found on pages 23-24 of the survey presented in appendix 5.5).

Stroke Impact Scale-16

As with the HRQoL scales some physical function scales are condition specific and others are not. There are a plethora of physical function scales available. As this study was on stroke survivors, a stroke specific scale was deemed appropriate. The *Stroke Impact Scale- 16* (SIS- 16) developed at the Landon Centre on Aging, University of Kansas Medical Centre, was chosen. The 59 item *Stroke Impact Scale Version 3.0* measures emotion, communication, memory and thinking, and social role function

alongside physical function. The SIS covers the three components of the ICF and has demonstrated good test-retest reliability as a postal instrument (Moriello *et al.,* 2008). The SIS -16 is a 'stand-alone' edition designed to measure the physical function alone. This scale has been shown to suffer fewer ceiling effects than the commonly used Barthel Index (Duncan *et al.,* 2003). Self and proxy agreement on the SIS-16 has been found to be acceptable (Carod-Artal *et al.,* 2009). Due to the nature of certain stroke acquired impairments some respondents will have required assistance to complete the survey and as such this presented an advantage. Due to these advantages, the fact that the scale is stroke specific and is short in length it was chosen for the current project.

Demographic Questions

The purpose of collecting demographic data is in part so that one can 'get to know' the population. The demographic data gathered was typical including gender, age, marital status, ethnicity, religious affiliation, education, and employment.

Questions on Capital

This study was interested in exploring Bourdieusian theory and as such certain key questions needed to be included which would elicit data to enable a Bourdieusian analysis. As will have been clear from Chapter 2, there are a considerable number of thinking tools within Bourdieu's work. Certain thinking tools, for example the hysteresis effect, are ultimately based in the habitus and thus ultimately a subjective concern. Therefore, many of these concepts are complex and, it is the view of the author of this thesis, best explored qualitatively. The forms of capital, however, can be viewed as relatively objective and therefore more appropriate for use within a survey.

It should be noted, however, that social and cultural capital are still complex and multifaceted concepts and while the survey needed to enable some assessment of capital to be made, the interviews were where the majority of this data was to be collected.

Attempts to measure cultural capital are often based on asking people whether they engage in bourgeois activities such as listening to classical music, going to the theatre and visiting museums and whether the individual knows who key historical figures are such as Einstein or Van Gogh (see Sullivan, 2007; Savage *et al.,* 2013). This was perceived as a problematic way to gain insight into cultural capital as it does not account for what the individual actually *does* engage in and is ultimately measuring the individual's level of cultural capital as dictated by the elite thus denying the possibility for 'local' cultural capital and leaves practical skills and specific forms of knowledge unaccounted for. Rather than attempting to assess cultural capital in this manner it was deemed more appropriate to ask the respondents questions on engagement and thus questions on the individual's interests and activities engaged in both before and after the stroke were created (see questions 28-31 in appendix 5.5). Therefore rather than assessing whether the respondents engaged in 'high-brow' activities or held knowledge of the highbrow the survey asked what the respondents were actively engaging in bringing cultural capital back to the individual.

Social capital is to do with networks but also resources gained from the people within a network. Questions were created which asked how often participants met with and

talked with family, friends, neighbours and former work colleagues. These social groups were chosen as they were deemed able to capture the differing types of people who are *likely* to be within any given individual's social network. Asking how often participants met with and talked to such groups meant that those with functional impairments, who found meeting with people they know problematic, were not inappropriately perceived as having less social interaction. The survey also asked for marital status and whether family members lived nearby. Having a spouse would indicate that the respondent experienced contact with another person on a daily basis and having family nearby would suggest the potential for increased practical support as families typically represent the main point of care for stroke survivors (Bugge *et al.,* 1999; Bhogal *et al.,* 2003; Pierce *et al.,* 2006; Denno et al., 2013). Being single without family nearby would suggest that an individual may lack such support. Finally the survey asked about club membership including membership in a stroke support club. Being a member of a club can provide access to an array of individuals with whom one shares an interest and therefore can perform as a form of social capital solidified by the social libido or illusio. Being a member of a stroke support club would suggest that the individual has formed new networks following their stroke (questions relating to social capital are questions 32-38 in appendix 5.5).

Merely meeting with and talking with people within one's network does not mean one is gaining a resource of support or a sense of connection with those within their network. Therefore, questions were developed to capture whether the respondents were gaining a sense of inclusion from their network and also whether they felt their friends or family relationships had altered (see question set 39 in appendix 5.5). In

addition to the novel questions designed to explore social capital, the BOSS contains a sub-scale on social relationships which also provided insight into any potential changes within the participant's social capital.

These novel questions were developed via brain storming sessions with the supervision team. In order to aid the study a project steering group which included those with expertise in the care of stroke patients, such as a speech and language therapist and a stroke consultant, as well as two stroke survivors with aphasia was formed. The steering group were met with periodically during the course of the study. The initial questions were presented to the steering group and reviewed for appropriacy and amendments made.

Survey Appearance & Layout

As is explained later in this chapter a varied sample was sought for the survey to represent the considerable variation within the population of stroke survivors. This meant that the survey needed to be accessible to those with communication and cognitive impairments. Before the survey was finalised the author attended a course on including people with communication disability in stroke research run by *Connect*, a charity for people living with aphasia, and referred to their literature for key steps to improve accessibility. *Connect* recommend using appropriate visual aids, simple syntax, bolding of key words and increased levels of white space within written documentation. These techniques were employed within the survey and reviewed by the two stroke survivors with aphasia and a speech and language therapist from the

project steering group to ensure their appropriacy. Due to the presence of pictorial aids and to improve the attractiveness of the survey colour ink was utilised.

The survey was called the *'Life After Stroke'* survey highlighting its relevance to the population. The layout of a survey is important, requiring a logical order. It has been recommended that demographic questions be placed at the end of a survey due to their potential sensitivity (Sudman & Bradburn, 1982; Simmons, 2001). However, within the survey the demographic questions were placed at the beginning under the belief that such questions are straightforward to answer allowing the individual to ease-in to the survey. Starting the survey with, for instance, the HRQoL scale could be too personal. A note of thanks was placed at the end of the survey and respondents were asked whether they were willing to be contacted for an interview and whether they had received assistance in filling out the survey.

Reviewing & Piloting the Survey

The project steering group reviewed the survey, assessing the questions for appropriacy, potential biases or leading language and also the accessibility of the questions. Following this the survey was piloted with 15 members of a local stroke support group. Following a large group discussion, 5 individuals also took part in a focus group to review the survey. Again this piloting process was concerned with accessing the appropriacy and acceptability of survey questions but also to check for potential errors and layout problems. Furthermore, it also offered a chance to check the survey database, created in SPSS, for errors.

Reliability & Validity

A copy of the survey has been provided in appendix 5.5. The questions on the survey were all given face validity via discussions with the supervision team, project steering group and during the piloting process. The BOSS and SIS-16 are validated scales tested for reliability and validity, however Cronbach's α was conducted on each scale. The Cronbach's α provides the average correlation among the items within the scale. The outcome ranges from 0 to 1 with a higher value representing greater reliability and it has been suggested that for a scale to be reliable it should be 0.7 or above however 0.8 is preferred (Pallant, 2007: 6 and 98). The results of the Cronbach's α are presented in appendix 5.6. Unsurprisingly the validated scales both achieved Cronbach's α of 0.8.

Limitations of the survey

A key limitation of the survey was its length. There are 33 pages and a total of 126 questions. Longer postal surveys can suffer lower response rates (Edwards *et al.,* 2002; Sahlqvist *et al.,* 2011). The survey was designed to be filled out by a population of stroke survivors, many of whom would have problems with fatigue, visual disturbances or other cognitive impairments, which would make filling out the survey problematic. As such the length of the survey may have had a negative impact on response rates. Two key approaches were used to make the survey more accessible. Firstly, the amendments made to aid those with communication impairments as outlined above. These amendments were also perceived as helpful for those with other cognitive impairments by both the steering group and the stroke survivors who were involved in the piloting process. Secondly, those with difficulties in completing the survey were encouraged to seek 'communicative assistance'. At the beginning of the survey, on the instructions page, a list of potential helpers was supplied (a relative, a friend, a speech

and language therapist or another healthcare worker) to make respondents aware of their options for completing the survey. Respondents were asked to indicate whether they received assistance at the end of the survey. As this study was predominately a qualitative study the number of questions asked within the survey could have been reduced or simplified as ultimately it was the interview data which held most importance. Perhaps too much information was requested within the survey. Increased piloting work could have resulted in a more succinct survey tool.

5.3.2: Development of Personalised Interview Guides

It is worth noting that all interviews are co-created by the interviewer and interviewee. If the interviewer uses a topic guide as though it were an interviewer- administered survey, and thus not allow the interviewee time to discuss issues which are salient to them, the interviewer may miss out on relevant and rich data. In a sense interviews are an opportunity for individuals to tell their 'story'. As Seidman states, stories are a '*meaning making process'* (2006: 7); they can enable the interviewee (and interviewer) to make sense of the issues under discussion. It is unlikely for this meaning making process to fit within the confines of a rigid topic guide. It is also not uncommon for unexpected topics to arise during an interview, which the guide does not account for, but could be relevant to the research (Keegan, 2009). When such a situation occurs the topic guide can be left to one side until the interview needs to regain some direction.

With the issues discussed above in mind the interviews were conducted in a semi-structured manner utilising a topic guide. The topic guide was developed to provide some direction to the interview; an aide-memoire. The guide aided consistency of the

interviews, however its utility was context depended due to the variety of responses and circumstances of any given interview. The guide itself was split into broad sections and designed to have a sense of chronology. As the key issue within these interviews was having a stroke the first topic in the guide was the stroke. However, it would be insensitive to move straight into such a topic without providing adequate time to develop a rapport with the interviewee. Therefore the topic guide begins with a simple check list which included thanking the interviewee for their participation, reiterating the purpose of the research in layman's terms and ensuring the interview consent form was signed. This provided a chance to 'break the ice' before moving into the interview itself and ensured that signed, informed consent was gained.

The topic guide was designed to cover 5 key areas:

1. Having the stroke and experience of care: contextualising the interview
2. Family and social network: social capital
3. Employment and finances: to gather data on economic capital and also cultural capital in terms of employment status
4. Hobbies, activities and interests: cultural capital
5. Sense of self: to gather data on how potential alterations in life situation and ability to maintain and accumulate capital impact upon the habitus.

As mentioned above the first section, which concerned the experience of having a stroke and provided a chance to set up rapport however it also enabled the interviewees to begin to discuss their experiences within the context of the bodily impact. This provided a qualitative perspective of lasting impairments and highly relevant data on bodily experience crucial to understanding the processes of

embodiment. Additionally colleagues within the project steering group advised that such an approach would be the most favourable as, according to these colleagues, stroke survivors are most likely to provide such data without prompting and thus could provide a natural starting point. The second topic of family and friends was specifically designed to gather data on the interviewee's social capital with a focus not only on the connection to particular networks but the resources these provided. A key aspect of Bourdieusian thinking is the embodiment of the social world within the body revealed through the bodily hexis. The data gathered on support and the influence of the attitudes of others, for example, could be utilised to explore the processes whereby such issues could influence action and practice. Data on family, friends and work colleagues also enabled data to be gathered on how the interviewees negotiated their social capital with acquired impairments and manoeuvred within social-spatial fields and whether this had resulted in alterations in practice and social interaction. The discussion on employment and finances was designed to gather data on economic capital and cultural capital. Unemployment can be common following stroke and the loss of employment could have an impact on sense of self within socio-spatial fields. The section on hobbies and cultural capital was designed to explore whether the loss of the ability to engage with valued hobbies and interests had an impact on the individual's habitus and thus hexis. Detachment from such aspects of identity could have an impact on the individual's embodied sense of self. The final section was designed to look specifically at sense of self. Utilising this at the end of the interview provided the opportunity to access data on embodiment which the preceding sections may have missed. Furthermore the preceding sections would have hopefully enabled the interviewee to reflect somewhat on their experienced as a stroke survivor and thus this last section would be able to capture such reflections. This meant more subjective

and in-depth data on these topics could be gathered. The final stage of developing the interview guides involved reviewing each interviewee's survey responses and developing personalised probes based on how they had answered certain questions within the survey (see appendix 5.7 for an example).

A non-personalised interview guide was piloted with colleagues and two people with aphasia from the project steering group. Following this relevant alterations in wording were made. This also provided the opportunity to work on interviewing skills prior to entering the field.

Limitation of the Interview Guides

As the interview guides were personalised each interviewee was not asked the same specific questions. This meant that the resulting interview data from each individual interview would ultimately be different and thus direct comparison between the data can be viewed a problematic. However, direct comparisons were not sought here. The intention, as discussed below, was to analyse the data thematically utilising, and exploring theoretical concerns. Furthermore, the subjective, personal account of experiences was the object of inquiry and as such directly comparable data was not of particular concern. However, the fact that each guide maintained the same order and sought to cover the same distinct sections does mean that some standardisation remained.

Social network board

Visual aids or props are common place within face-to-face interviews for dealing with complex issues and can be highly useful for interviews with children and those with disabilities, such as learning disabilities, dementia or communication impairments (Price & Goodman, 1990; Goodwin & Goodwin, 1996; Hatch, 1995; Dalemans *et al.,* 2009). The piloting stage of interview guide development revealed that discussing social networks was a complex task. In order to simplify the process a visual aid was developed so that interviewees could plot out their network. Tactile communication boards and *Talking Mats* have all been used to aid discussions with adults and children with communication impairments both in healthcare and research settings (Murphy & Cameron, 2008; Murphy *et al.,* 2010; Murphy & Boa, 2012). With this in mind, and following the brainstorming session with the supervision team, it was deemed appropriate to create something tactile, using stick-figure style models which could be physically lifted and moved if necessary for the interviewees to plot out their network.

Synthetic rubber sheets were used to create the 'stick figures' which were cut out using small ginger bread men and women biscuit cutters. As individuals are not always able to meet with people in their network face-to-face, small telephone symbols were created designed to be placed on individuals or groups with which contact was made mostly by telephone or the internet (email or through social networking sites). Coloured pipe cleaners were used to highlight connections between people within the network if this was deemed necessary to highlight. The cut out figures, phone symbols and connections are pictured in Figure 5.2. The board itself was a mobile jigsaw board. Such boards are designed to keep jigsaw pieces in place with a non-slip surface which

was therefore able to keep the cut-out figures in place. The stick figures were cut out in 5 different colours so that various groups or types of people could be plotted on the board. For example, the colour red could be used to represent family members while green could be used to represent work colleagues. Once the figures were ready the board was tested on colleagues to see how best to plot the figures on the board. Each person was asked to think of the people they know and plot them on the board. This appeared to work well and the discussion of social networks, with the aid of the board, was easier to conduct than without. A camera was taken to each interview in order to record each interviewee's network. These photographs were used as visual aids within the analysis stage. An example of a completed social network board is presented in Figure 5.3.

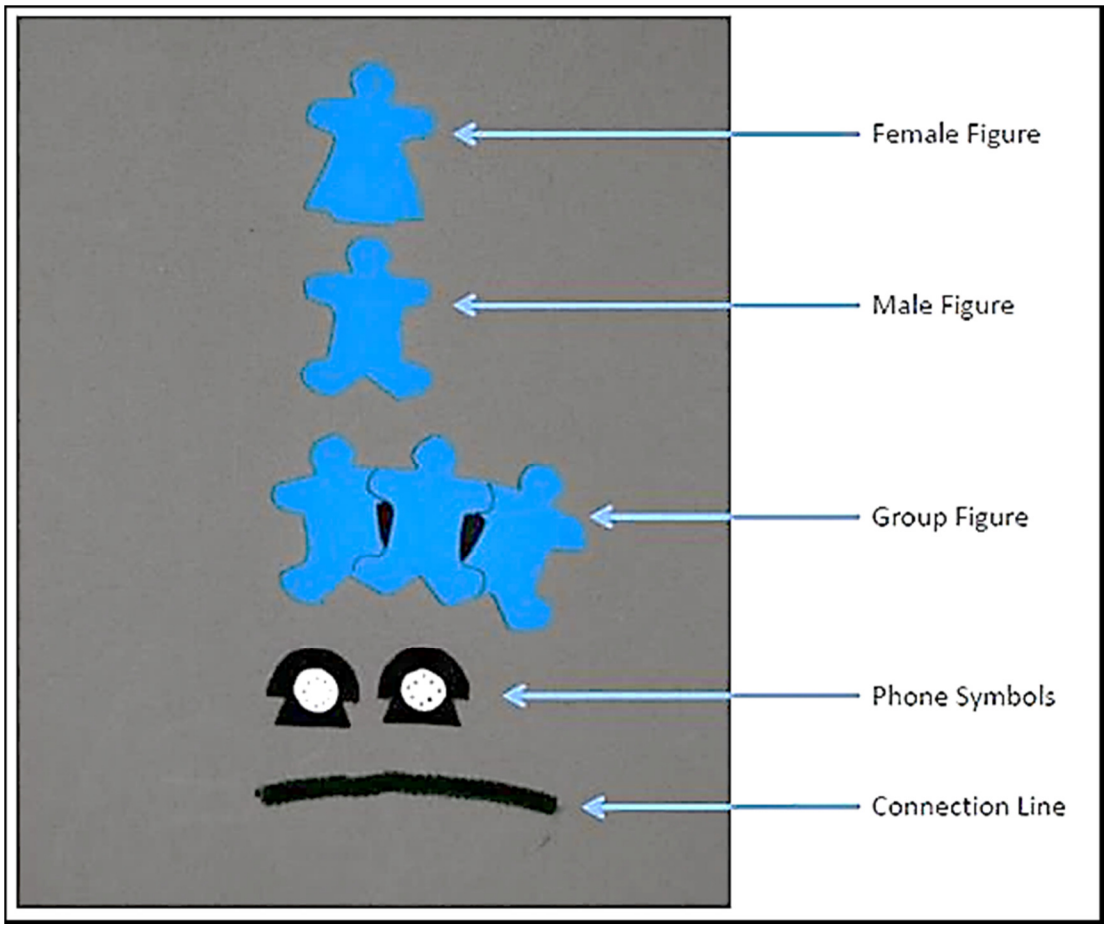


Figure 5.2: Social Network Items

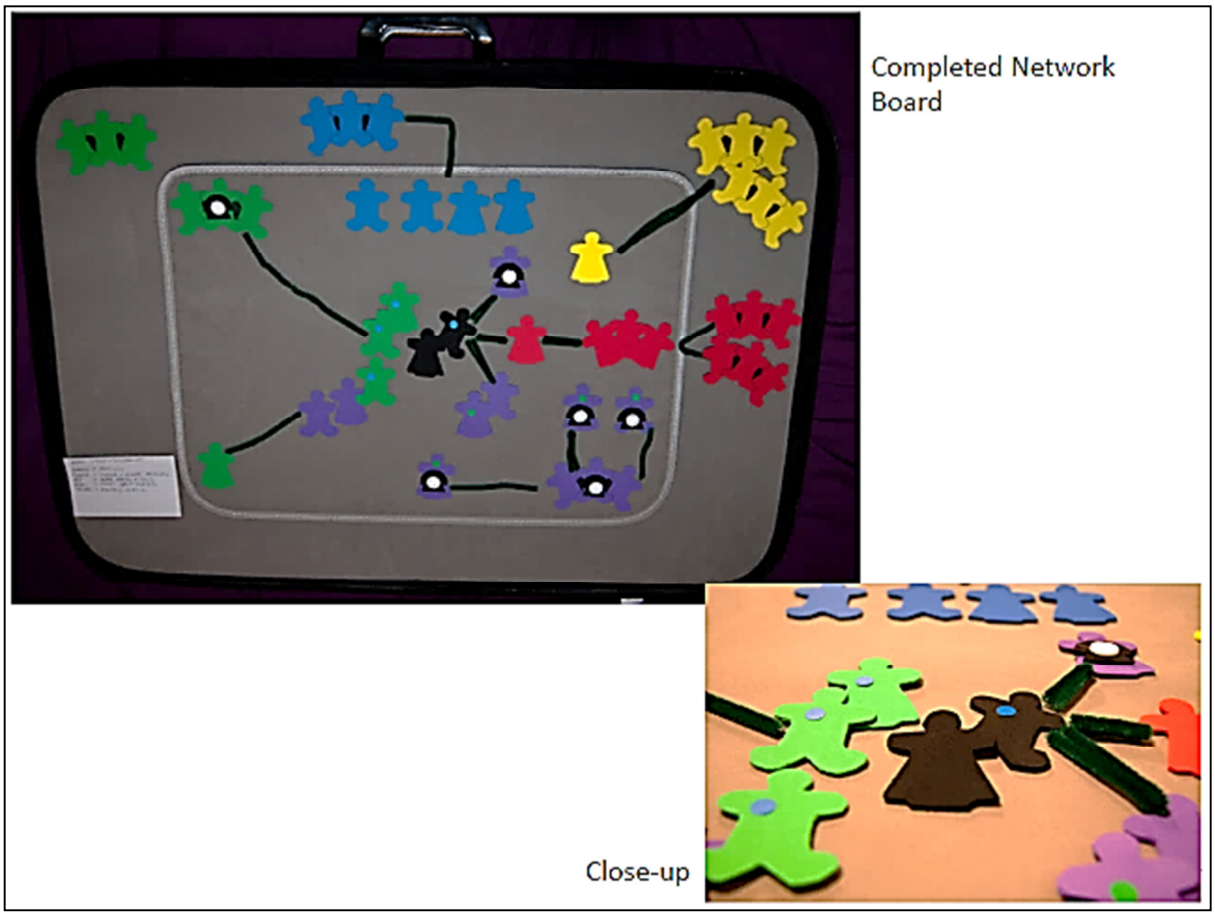


Figure 5.3: Complete Social Network Board

5.4: RATIONAL FOR THE SAMPLING PROCESS

This study was qualitatively orientated and the key method of data collection was semi -structured in-depth interviews. Sampling for qualitative studies often relies on non-probability sampling such as convenience or sampling by chance, for example, recruiting participants from patients attending a clinic. Such a strategy would ultimately mean that the final sample would be based on those who attended the clinic within the timeframe of recruitment and the researcher would have to 'make do' with those who agreed to take part as opposed to having the luxury of being selective about who to interview. Another often used sampling method for qualitative approaches is 'snowball' sampling where the networks of interviewees or others

involved in the research, such as gatekeepers, are used as a source for potential interviewees. Snowball sampling can be a highly useful method for accessing so called hard to reach populations, such as drug users or sex workers (Johnston & Sabin, 2010). However, much like sampling by convenience, snowball sampling does not ensure diversity and also takes much of the power for selecting interviewees out of the hands of the researcher. In order to bring selection into the sampling process and enable the researcher to ensure a level of diversity within the sample population, qualitative researchers can make use of pre-existing sources such as administrative records, published lists or a pre-existing survey sample (Ritchie & Lewis, 2003). However, while administrative lists, published lists and pre-existing surveys samples can provide the opportunity to actively select the interviewees, they may lack the forms of information which the researcher would ideally like to know when selecting interviewees. By creating a novel survey designed specifically to generate a diverse sampling pool, the researcher can guarantee a varied interview sample selected based on information deemed of interest to the research. This strategy was adopted here.

The Health Informatics Centre (HIC) is a research centre affiliated with the University of Dundee and Ninewells Hospital. HIC holds a database of stroke occurrence within the catchment area of Ninewells Hospital. This database is known as the Dundee Stroke Database can be utilised for research purposes. Appropriate ethical approvals for this study were acquired prior to such data being accessed[11]. This pre-existing list

[11] All research projects conducting research concerning NHS patients must acquire appropriate ethical approvals. Ethical approval for this study was granted from *NHS Tayside Committee on Medical Research Ethics (A)* and Caldicott Guardian Approval and an honorary contract with NHS Tayside were gained prior to the recruitment. *Good Clinical Practice* training was achieved ensuring awareness and adherence to ethical guidelines. An outline of key ethical issues have been outlined in appendix 5.1,

provided the opportunity to begin a process of actively selecting potential respondents for the current study. However, while this list provided enough detail to begin narrowing down the population to those deemed most suitable to the study, there was not enough detail to pin point key individuals for interview. Therefore a novel survey tool was developed, as outlined above, and utilised to a) access a population spread out over a large geographical area, b) remove reliance on convenience or snowball sampling and c) enable a process of purposive sampling for interviewee selection.

5.4.1: Sampling for the Postal Survey

While survey tools are typically associated with quantitative analysis and thus usually seek a representative sample this was not the concern of the current study. The chief aim was to select a sample which reflected the diversity of the population concerned; not representative in a statistical sense but representative in a thematic sense. This was because statistical methods, which aim to make generalizable claims about the population, were not of interest. However, as will be outlined in the discussion of sampling for interviewees, statistical procedures were used to categorise survey respondents. This was for practical and pragmatic reasons to enable the creation of purposive sampling grids.

The inclusion and exclusion criteria for the survey phase are presented in Figure 5.4. As the brain, the functioning centre of the body, is affected by stroke the potential outcomes for the individual are highly varied. Depending on the area of the brain that

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copies of approvals have been provided in appendix 5.2 along with copies of the information letter and consent form in appendix 5.3-4

is damaged and the extent of that damage, the individual could be left with varying physical and / or cognitive impairments, which hold their own challenges for social interaction. Also, the individual is at greater risk for secondary strokes which can lead to further impairment and thus potentially further challenges. This ultimately means that the global population of stroke survivors as a whole is considerably diverse on the grounds of the impairments experienced. As the personal, subjective experience of living with stroke rests at the heart of this thesis, capturing that variation was of great importance. Therefore, the postal survey used a highly inclusive inclusion criteria aiming to produce a sample of stroke survivors with varying types of physical and cognitive impairments, and number of strokes. This included people with communication impairment. People with communication impairments such as aphasia are commonly excluded from stroke research due to the perception that they may not fully understand what is being asked. As Dalemans *et al.* state there is a '*pattern of recruiting only those individuals who have the competence to express their perspective, or to express verbally with a reflective and clear style*' (2008: 948) within research. People with aphasia can experience a considerable amount of social exclusion due to the presence of their impairment (Hilari & Northcott, 2006; Hilari *et al.,* 2010; Northcott & Hilari, 2011). Opting to exclude people with aphasia at the outset of a study, while often justifiable on practical grounds presents yet another form of exclusion to this population and leaves the impact of communication impairment ignored or sectioned off within research on the post-stroke experience. The current study sought to include people with communication, and cognition problems where possible in order to attempt to present the considerable diversity that exists within the population of stroke survivors.

This thesis sought to understand the experience of stroke survivors within the chronic phase of their condition. This meant gaining access to individuals who had passed the hospitalisation and rehabilitation phase of their recovery and were living within the community. Buscherhof, describing her own experience of stroke, stresses that the stroke event is the beginning of a transitional experience which '*spans many years'* (1998: 26). Stroke survivors can face many potential adjustments both physical and psychosocial as well as life-style changes such as occupational change or living arrangements. This meant that time for personal adjustment need to be allowed for. As such 3 years post-stroke event was deemed an acceptable cut-off point as this would provide some time for individuals (and their families) to adjust, at least to some degree, to the changes thrust upon them. The higher end cut-off point was set at 12 years post-stroke. By recruiting stroke survivors whose initial stroke was over a decade prior to the research the longer lasting impacts could be explored.

While stroke is more likely to occur in those aged 65 years and over it can occur at any age and is prevalent among adults aged <55 years (Lawrence & Kinn, 2013). This study sought to recruit younger stroke survivors of working age with the age of 45 years chosen as the lower age cut-off point. As time since diagnosis was 3 to 12 years this meant the respondents would have potentially experienced their stroke event during their mid-30s through to their older age. This meant that the sample would include those whose stroke occurred during their working lives, possibly with dependents to look after, through to later retirement enabling considerable life-course variation within the sample.

Figure 5.4: Inclusion and Exclusion Criteria for the Postal Survey

Inclusion Criteria	Exclusion Criteria
Diagnosed with any type of stroke	Diagnosed with a transient ischemic attack (TIA)
Any form of physical or cognitive impairment	Severe cognitive impairment which would prevent informed consent or present a potential for harm
Diagnosed between January 1998 and December 2007	Diagnosed before January 1998 and after December 2007
Living in the community	Those residing in nursing homes or other care facility
Aged 45 years and above	Aged of 44 years or younger

Access & Recruitment for the Postal Survey

HIC screened the Dundee Stroke Database for the inclusion and exclusion criteria and 801 potential participants were highlighted. Information packs for the study were sent to potential participants through the post. These packs detailed what was involved in the study. Non-responses were followed up 2 months later. No further correspondence was attempted following second non-response. Those who agreed to participate (n=607) were asked to complete a postal survey. Within this survey they were also asked whether they would be interested in taking part in an interview. This meant that those who did not wish to be interviewed were known prior to interviewee selection (the response rates for the survey have been provided in appendix 5.8).

The data from all respondents, including those who declined to be interviewed has been shared with HIC for secondary analysis providing them with in-depth data on the

population of stroke survivors within the catchment area of Ninewells Hospital. The full survey sample was not of concern to this thesis except for sampling for the interview phase.

5.4.2: Sampling for Interviews

The sample size for qualitative research is generally smaller than those for quantitatively focused research. In qualitative studies more data does not necessarily mean more information or understanding. This is, in part, because qualitative data is not as concerned by frequencies of items of data as in quantitative research. A single incidence of a code or piece of data *can* be as valuable as many occurrences in aiding and developing an understanding of the phenomena; qualitative research is typically concerned with meaning in context. Furthermore qualitative data collection and analysis are both time consuming processes making a large sample unrealistic within resource and time limited studies. The notion of reaching a saturation point, where it is likely that new data will not produce new information, is sometimes viewed as the desired point to reach in qualitative research (Saumure & Given, 2008). However, saturation can be viewed as a '*matter of degree*' in that there will always be the potential for '*the new to emerge*' (Strauss & Corbin, 1998 [1990]: 136) depending on how many individual researchers are involved in analysis and their theoretical perspective, how much time can be spent on analysis and also whether there are different periods of analysis, for example, coming back to the raw data at a different time with a new set of enquires. Approaching data with the explicit aim of reaching saturation can be '*counter-productive*' (*ibid*) as the potential new discoveries may not enhance understanding of phenomena or enable further theory development. For this thesis the sample needed to be large enough to provide an in-depth understanding of

phenomena in relation to the research questions but small enough to avoid a situation where there were too much data or that the data became repetitive (Sandelowski, 1995). As such 25 to 30 interviews were deemed enough to gain an in-depth understanding, but also avoid a situation where the researcher would be 'swimming in data' or analysing data which were ultimately superfluous.

Despite the fact that sampling for the interviews was based on survey respondents who had indicated that they would be willing to take part in an interview, some of these respondents may have changed their mind or become unable to take part in an interview. Therefore 36 individuals were selected and invited to take part to ensure the target number of interviews could be achieved.

As mentioned above, a process of purposive sampling was utilised for the selection of interviewees. A diverse sample was sought in order to gain rich data that could expose the contextual issues which could impact on the post-stroke experience and the embodiment process. The form of purposive sampling utilised was based on the principles of both maximum variation and theory guided approaches. As the name suggests maximum variation sampling is a form of purposive sampling which seeks to identify individuals whom cover the range of positions or perspectives in relation to the phenomenon under study (Ritchie & Lewis, 2003). Theory guided sampling is where theoretical considerations influence the criteria by which individuals are selected (Ritchie & Lewis, 2003). A varied sample was sought in order to heighten the chances of exploring the range of experiences and perceptions of living with stroke

from those in varying circumstances. As the thesis aimed to utilise Bourdieu's theoretical toolkit to inform analysis, sampling which was guided by identifying individuals who would enable an in-depth exploration of these concepts was deemed appropriate.

The process of purposive sampling was an iterative one whereby potentially interesting cases were highlighted, reconsidered against other possible cases for interview, compared, and then the numbers reduced and finalised. The true beginning of this process occurred as surveys were being logged into the survey database; survey respondents who left a comment within the open-ended comments section which was relevant to the research or whose answers within the survey presented potential contradictions were noted as 'potentially interesting cases'. However the bulk of the process involved the creation of sampling grids within Microsoft Excel based on key criteria as outlined below.

Missing data

Before the process of purposive sampling could be undertaken missing data needed to be considered and coded. When data or values are missing some statistical procedures will not work as well or at all (for example, regression analysis). While statistical analysis of this manner was not a concern for this study, if items of missing data were not dealt with this could potentially impact upon the process of sampling. As survey responses were put into the SPSS database any items which were missing were coded as missing so that such instances were recognisable.

Within the sub-scales of the BOSS where data were missing the average item response value for the completed items in that sub-scale was computed. This average score was then imputed as the value for the items with missing data. The same process was utilised for the SIS-16 and rudimentary scales (outlined below). However, if fewer than half of the items in the SIS-16, BOSS or BOSS sub-scale were responded to, that average score could not be computed and thus each missing value and the overall scale score were coded as missing.

Purposive sampling process

This thesis aimed to explore not just the experiences and perceptions of living with stroke in the long-term but also explore Bourdieu's theoretical toolkit. This meant that in sampling for the interviews, data within the survey which provided some indication as to the individual's social and cultural capital, the individual's well-being and of course the individual's functional, communicative and cognitive capability were the primary criteria for sampling. Other information present within the sampling grids were data on age, gender, and employment. Further contextual data used for the purposive sampling process were a) Scottish Government's (2009-2010) 6-fold Urban Rural Classification (Scottish Government 2010) and b) Scottish Index of Multiple Deprivation (SIMD). Such data was identified by utilising postcode data. The urban / rural classifications are detailed below:

- Large Urban Areas: Settlements of over 125 000 people
- Other Urban Areas: Settlements of 10 000 to 125 000 people

- Accessible Small Towns: Settlements of between 3 000 and 10 000 people and within a 30 minute drive time of a Settlement of 10 000 or more
- Remote Small Towns: Settlements of between 3 000 and 10 000 people and with a drive time between 30 and 60 minutes to a Settlement of 10 000 or more
- Very Remote Small Towns: Settlements of between 3 000 and 10 000 people and with a drive time of over 60 minutes to a Settlement of 10 000 or more
- Accessible Rural Areas: Areas with a population of less than 3 000 people and within a drive time of 30 minutes to a Settlement of 10 000 or more

The reason for considering urban and rural residency within the sampling frame was due to the potential impacts of the urban verses rural environments on the experiences of living with stroke. For example, living within a large urban area could result in better access to services as well as access to valued places such as the local pub, club or cultural settings such as galleries and cinemas. Urban settings are also densely populated which can increase the potential for social interaction. However, the inherent business or noise could prove problematic for stroke survivors. Urban environments can present hazards of heavy traffic and poorly maintained pavements which can make negotiating the environment problematic (Logan, Dyas & Gladman, 2004; Clarke *et al.,* 2011). Rural environments are likely to be quieter, however gaining access to services or desired locations can become problematic. Many stroke survivors will no longer be able to drive (Fisk, Owsley & Pulley, 1997; Fisk, Owsley & Mennemeier, 2002), which can restrict social participation and independence (White *et al*., 2012), and many will avoid or feel unsafe using public transport (Logan, Dyas &

Gladman, 2004; Wendal *et al.,* 2010; Risser, Iwarsson & Ståhl, 2012). As such rural environments can present considerable restriction in activity participation, social interaction and independence.

The SIMD identifies concentrations of socio-economic deprivation across Scotland (Scottish Government 2009b). It is based on small area data zones containing, on average, 750 people creating 6, 505 data zones in total. These data zones are real geographical areas. The overall SIMD is based on the weighted sum of seven domain scores each of which encompass a certain aspect of deprivation: 1. Current income deprivation, 2. Employment deprivation, 3. Health deprivation, 4. Education, skills and training deprivation, 5. Geographical access, 6. Housing deprivation, and 7. Crime. The data zones can then be ranked. A data zone which is ranked 1 will be most deprived while a data zone ranked 6, 505 will be the least deprived. It is thus a relative measure of deprivation. The measure can identify the most deprived small areas on both the overall index and each of the individual domains. This can be done by employing cut-off points such as 5% (vigintile) 10% (decile) or 20% (quintile). Using the 20%, or quintile cut-off point, creates 5 groups, those in quintile 1 would be areas which are most deprived and those in quintile 5 would be least deprived. As such the SIMD can be utilised to provide data on economic circumstance and provide a somewhat arbitrary indication of possible class background. An individual's environmental and socio-economic circumstance and surroundings will impact upon the individual's habitus and as such the SIMD was deemed to be a useful tool to aid purposive sampling in order to ensure a sample from diverse socio-economic backgrounds. The

quintile cut off points were utilised here to classify participants within the purposive sampling grids.

Creating the sampling grids involved organising key data from the survey in a manner which easily categorised the respondents. The survey contained considerable data on each respondent and therefore, for pragmatic and practical reasons, rudimentary scales were developed to separate the respondents into those who had either high or low social and cultural capital alongside the standardised scales used for HRQoL and physical function as well as subscales for communication and cognition.

Questions on how often the individual met with and spoke with friends, family, current or former work colleagues and neighbours were used to form a rudimentary scale for social capital. Questions on social relationships were used to form a rudimentary scale, labelled 'sense of inclusion', to gauge how connected they felt to those within their network therefore supplementing the social capital scale. Questions on interests and activities were used to create a rudimentary scale for cultural capital. These scales underwent face-validity tests via discussions with the supervision team and project steering group and Cronbach's α were run to assess the reliability, or more specifically, the internal consistency of the novel scales (see appendix 5.6). The scales were not tested for convergent, divergent or predictive validity. Therefore, it should be noted that there is no evidence that these scales accurately measure what they intend to measure. However, the rudimentary scales were not meant to be valid scales which could be used to test for relationships via statistical measures and make any claims of generalisability; the sole purpose was to enable the respondents to be categorised for the purposes of sampling.

The rudimentary scales and validated scales are continuous variables. In order to aid the process of sampling these variables were recoded into categorical variables using a process of visual binning (see Figure 5.5). Cutpoints at fixed standard deviation intervals around the mean were used to create four categories from each variable:

1: Lowest scoring

2: Second lowest scoring

3: Second highest scoring

4: Highest scoring

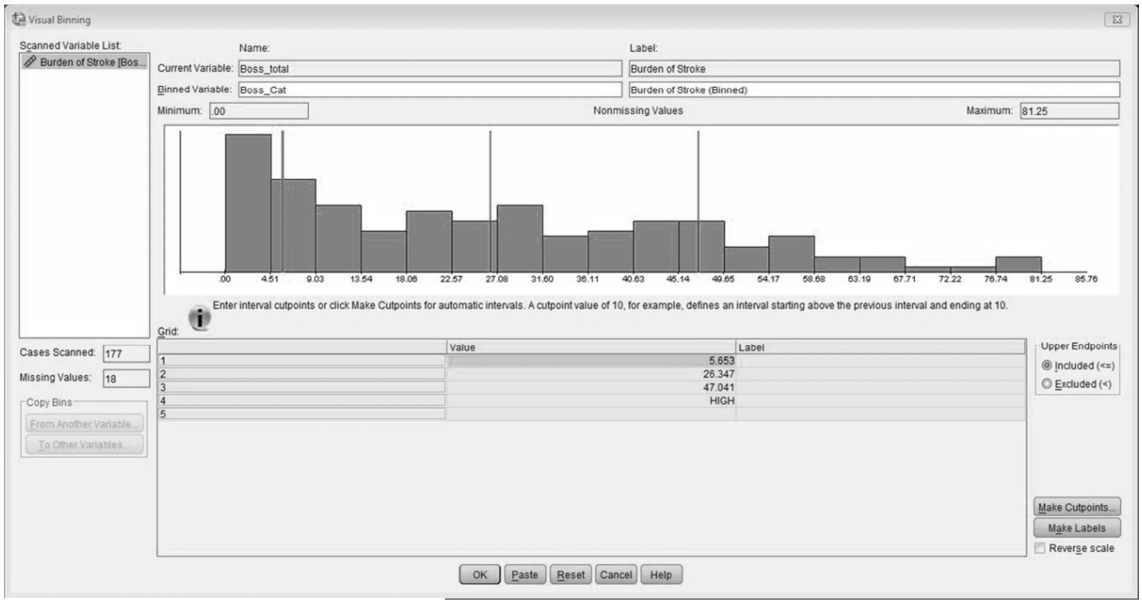


Figure 5.5: Visual Binning

Four of the respondents within the survey sampling pool did not provide enough data on the BOSS for an overall score. These respondents were removed from the visual binning process for the BOSS. However, these respondents were not removed from the sampling grids as they had provided enough data for the other items on the grid to

be filled. The sense of inclusion rudimentary scale was used as an arbitrary proxy for the BOSS for these respondents.

The questions on employment also gave an insight into both social and cultural capital; the skills required for employment suggest an accumulation of cultural capital and *context specific* cultural capital as well as suggesting a certain form of work related social capital. As such the respondents were placed into 3 separate grids:

1: Currently employed and employed before stroke

2: Currently unemployed and employed before stroke

3: Unemployed before and after stroke

The decision to create three grids based on employment was again a pragmatic choice made for visual simplification and to ensure that there was variation within the interview sample based on employment. An example of a completed sampling grid has been provided in Figure 5.6 below[12].

[12] Please note Figure 5.6 is a replication created to aid explanation of the sampling process. The original grids were, at the end of the sampling process, marked with pen, highlighter and notes or 'memos'.

Currently Employed Sampling Grid											
Interviewee ID	Gender	Age	Urban or Rural / SIMD	Cultural Capital	Change in CC	Social Capital	Sense of Inclusion	HRQoL	Function	Cognition	Communication
186	M	56	U Qn5	4	-	3	4	4	3	4	3
213	M	65	U Qn3	3	v	3	2	2	3	3	3
220	F	66	R Qn4	2	-	3	4	3	4	4	4
330	M	55	U Qn4	3	^	4	2	3	3	3	4
500	F	57	U Qn2	2	v	3	2	3	3	4	2
525	M	57	R Qn4	4	-	3	3	4	3	4	4
536	M	59	U Qn3	2	-	2	3	3	3	3	3
542	M	58	R Qn4	3	v	3	4	3	4	3	4
563	M	53	U Qn3	4	-	4	3	4	4	4	4
578	F	48	U Qn4	3	-	3	3	3	4	3	3

Figure 5.6: Purposive Sampling Grid

Interviewee Recruitment

Seventy of the survey respondents indicated that they would be willing to take part in an interview (see appendix 5.8 for survey response rates). Thirty-six individuals were selected via purposive sampling. Potential interviewees were contacted by post. Each received an invitation with contact details, a reminder of the study's aims and purpose, and an availability sheet. The availability sheet contained a section for them to provide a reason if they chose to decline. Interviewees were also asked whether they would like to be interviewed at the University, within their home or another venue of their choosing. These selections meant that if an interviewee had mobility problems they could be interviewed at home and therefore not need to organise travel, for example. Also, if they were not comfortable having a stranger interview them in their home they could have the interview elsewhere in a more neutral environment. A freepost envelope was provided for them to return their responses. As with the survey and information sheets, the invites to interview were also written with increased white

space, simplified syntax and bolding of key words to make them accessible to those with communication impairments. The interviewees were asked to fill in an interview consent form before beginning the interview. These were also made accessible for those with communication impairment.

Sampling for the Instrumental Multiple Case Study

The process of sampling for the case study analysis was also one of purposive sampling. However, rather than seeking variation, the cases selected were done so in order to enable explanation building. An instrumental case study is the study of a case, or multiple cases, with the intention to provide greater understanding of a particular issue or to expand theory; the case itself is secondary to understanding the phenomena (Mills, Durepos & Wiebe, 2010). Purposive sampling can be especially helpful if interesting or particular cases are sought as it allows the researcher to select:

> *"… information-rich cases for in-depth study … from which one can learn a great deal about issues of central importance to the purpose of the research …"* (Layder 1998: 46).

Therefore, cases were chosen which best exemplified key theoretical issues. The initial thematic analysis undertaken to explore the data (see below) produced a set of interlinked emerging themes which provided an opportunity for theoretical expansion and enabled the possibility to explain, in-depth, the impact of stroke on the individual habitus. These themes are presented and discussed in Chapter 7. Cases were chosen

which represented these themes by going back through the interview transcripts and noting which interviewees appeared to encapsulate these themes, comparing the selection and finalising the two cases which were deemed most appropriate.

5.5: Analysis

The main form of data analysis utilised within this thesis was theoretically driven thematic analysis. Thematic analysis has been defined as a process of:

> *"…identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic"* (Braun & Clarke, 2006: 79).

According to Braun and Clarke a theme should capture something significant about the data which is relevant to the research question and '*represents some level of patterned response or meaning within the data set*' (2006: 82). Within this thesis the data were considered with the guidance of the principles of Layder's adaptive theory approach in which theoretical considerations inform the process of identifying codes and themes. Therefore '*the search for new codes and concepts goes on in tandem with the use of extant theoretical assumptions*' (Layder, 1998: 55). The empirical data and theoretical considerations were linked in the process of analysis and the analysis was theoretically driven.

The thematic analysis process

The process of thematic analysis has been presented in Figure 5.7. The first stage of analysis was familiarisation which began in tandem with data collection in the form of memoing and diary notes used to capture early thoughts on potential codes or developing codes, and to keep a record of personal reflections on the tone of an interview. These notes and memos contained forms of data within themselves and were used to assist later coding. The process of familiarisation continued during the process of transcription where further memos were taken.

The second phase of the thematic analysis was generating codes. Qualitative analysis software, such as NVivo, is often used in the process of analysing qualitative data. However, while software can assist in the organisation and management of data the researcher will still need to uncover codes, create the categories and decide what data is salient; software will not '*do the analysis for you*' (Weitzman, 2000: 805) it will just remove the messy, tactile aspects of traditional manual coding such as the coloured pens, scissors and paper (Basit, 2003). Layder recommends the use of:

> "*… primitive pre-coding devices, such as underlining parts of the text or putting an asterisk by certain sections of text in order to highlight their importance or relevance"* (1998: 53).

This process was undertaken within this study as part of familiarisation phase and the identification of initial codes. A transcript would be read through alongside the

individual interviewee's survey responses and parts highlighted and memos created. This initial coding began to organise the data and the tentative codes were amended or strengthened later in the analysis process. This was an iterative process with the coding frame being revisited numerous times before the development of categories (grouping codes) took place. The grouping of codes was assisted by placing them within tables in Microsoft Word.

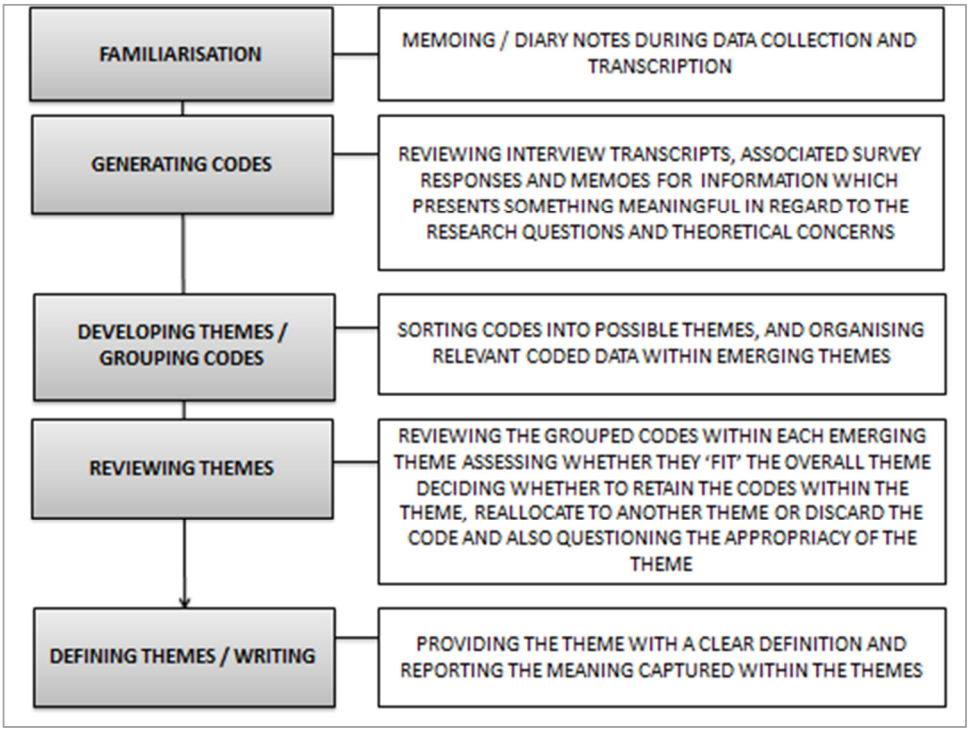


Figure 5.7: Analysis Process

As one codes data themes begin to occur to the researcher, that is, they emerge within the researcher's thought process. These emerging codes were noted in memos. Despite referring back to theory during coding it was tempting to become distracted by interesting issues presented with the data which did not directly concern the research questions and were somewhat removed from theoretical concerns. Therefore, before

codes could be grouped they needed to be reviewed on the basis of whether they were relevant to research questions or whether they linked to theoretical concepts. Codes or groups of codes which were not relevant were recorded but not presented within this thesis. These superfluous codes (and themes) could be returned to in the future. Themes concerned with social capital were prominent and appeared to be nuanced. As such these themes were focused on and mined in greater depth.

Once a series of codes had been finalised these codes were placed into categories and linked to emerging themes related to both theoretical concerns and research questions. The emerging themes required reviewing where the codes were reconsidered in relation the theme. The reviewing process anchored on 3 key questions: 1. Does this code say something meaningful in relation to the research questions. 2. Does this code belong within this theme, a different theme or both or should it be discarded. 3. Is it the code which is problematic or is the theme problematic? The first 2 questions are a matter of appropriacy of codes however question 3 was considered if it appeared that a number of codes did not truly link to the overall theme at which point the theme required revision or removal. Sometimes this was an issue of terminology where the tentative label given to a theme was misleading.

Once the themes were finalised they were defined. Taking the time to write down the definition of a theme was a highly worthwhile process as this crystallised the concepts. However, much of the in-depth analysis of the themes took place in the process of

writing about them. This aspect of analysis is often overlooked within the literature however, the act of engaging in explaining to an independent party what a theme means and how this theme illuminates the phenomena, and enables research questions to be answered, opens the mind and challenges one's own understanding of the apparent outcome of the analysis. Such themes become 'tweaked' somewhat once removed from analysis tables. These findings are presented in Chapter 6.

Case Study Analysis

In order to further explain the meaning of key emerging themes from the initial phase of the theoretically driven thematic analysis, and in turn gain a focused and in-depth understanding of the individual experience, a case study analysis was employed. In utilising a case study approach the thesis moved to focus more on detailed understandings of the phenomena and potential theoretical adaption. As mentioned earlier an instrumental multiple case study was used. The aim of the instrumental case study was not necessarily to discuss the cases but to use data from the cases to explain something abstract and theoretical. The use of more than one case was based in the interwoven nature of the themes the case study was meant to expand upon; using the 2 cases enabled explanations to be built.

There were 3 key stages: 1. Creating in-depth case profiles utilising interview data, survey data and memos created relating to each case. 2. Reviewing the profiles for key items of data which enabled the building of the theoretical concept (which was similar to thematic coding). 3. Writing-up each case. The true in-depth analysis occurred in the writing. The preceding stages, for the author of this thesis, were organisational acts

enabling data to be seen clearly while writing about what the data, in conjunction with further memoing to capture thoughts, and referring back to data, meant a deeper level of understanding could occur. The case study findings are presented in Chapter 7.

5.6: VALIDITY, RELIABILITY & LIMITATIONS

This thesis utilised a qualitative approach. A criticism often levelled at qualitative research is that the findings are produced subjectively within the mind of the researcher and therefore are not as straightforward to support or refute as those findings which are found via statistical techniques. Research conducted using focused quantitative methods can utilise appropriate sample sizes and statistical techniques to certify that findings are viewed as valid, reliable and generalizable to the reader. Research which has utilised a qualitative approach lacks the neat and tidy certification of statistical tests however issues of validity, reliability, and generalisability and the quality of the research should still be considered.

Reliability is concerned with the repeatability of findings while validity refers to the credibility or believability of the research. Assessing reliability in qualitative research is problematic due to the inter-personal process of data generation and the subjective nature of interpretation (Stenbacka, 2001). Quality of qualitative research however can be viewed as resting on openness; validity and reliability can be assessed if the process of producing the findings can be examined through the presentation of the decisions which were made and steps taken in the data collection and analysis process (Marshall & Rossman, 1995). Within this thesis the descriptions of analysis have been outlined above.

Credibility of research can be viewed as the qualitative researcher's answer to internal validity. Credibility '*involves the approval of research findings by either interviewees or peers as realities may be interpreted in multiple ways*' (Riege, 2003: 81). Credibility can be achieved via a debriefing process, in which data analysis, emerging concepts and conclusions are presented and discussed with colleagues as the study develops. For this thesis peers, colleagues, the project steering group and the supervisory team were all called upon for open discussion during the progression of the research. This enabled the analysis to be given critique, and reconsideration adding to its trustworthiness and credibility.

Sampling for qualitative research is unrepresentative in the sense that generalisability of findings to the wider population cannot be claimed. Within this study the issue of generalisability was not of great concern. The aim of this thesis was to attain a deeper understanding of a particular phenomenon and explore and expand upon particular theoretical concepts. However, the sampling process did take an approach which was representative in a thematic sense as the inherent variation within and between stroke survivors was aimed for. This approach was therefore also inclusive aiming to enable those with varying physical and cognitive impairments to take part.

The form of research undertaken for the attainment of a doctoral degree is, for the most part, a solitary endeavour. This can lead to a narrow or limited understanding of the data and emerging findings. This thesis was driven by theoretical curiousness which was, in many ways, personal and subjective. This could be viewed as problematic as another researcher could consider the same raw data and produce a

different theoretical perspective which could challenge the one presented here. However, this thesis has been open about its aims in which a *particular* set of theoretical concepts were used to explore a population and in turn these concepts expanded upon. The fact that somewhat different conclusions can be drawn from similar data is not, necessarily a fault with the research itself but more a reflection of the differences between individuals; the hypothetical other researcher would have had differing life experiences, read and specialised in different theories and therefore it would not be particularly surprising that their conclusions differed from those presented here.

CHAPTER 6: THE ROLE OF EMOTION IN THE NEGOTIATION OF SOCIAL CAPITAL & SOCIO-SPATIAL LOCATION AS A STROKE SURVIVOR

6.1: INTRODUCTION

The overarching aim of this thesis was to employ Bourdieu's theoretical tool kit to explore the experiences and perceptions of community dwelling, chronic stroke survivors. The previous chapters have presented the two key topics of concern, Bourdieu and stroke, as well as outlining the methodological approach utilised. The findings discussed within this chapter are the result of a theoretically driven thematic analysis. This required an iterative process of going back and forth between theory and data which ultimately resulted in a re-examination of the theory utilised. The purpose of this chapter is to present the findings of that analysis.

This chapter is thus concerned with how becoming disabled alters how an individual negotiates their social capital and their sense of social position in socio-spatial fields. It will be argued that social capital is not necessarily (re)produced by rational and respectful reciprocity but can be held together by emotional co-dependency, affectual obligations and loving dispositions. Furthermore, the emotions produced within socio-spatial encounters, as individuals negotiate their social capital, are characterised by sympathy, antipathy and *ambivalence*. These emotions can result in a (de)valued

identity which is further problematised by becoming disabled in a society where disabled bodies are still viewed as illegitimate and as the 'other'.

6.1.1: Chapter outline

The first section of this chapter outlines the interview sample. The thematic analysis revealed that emotions play a key role in the (re)production and negotiation of social capital and sense of place in social space. The second section of this chapter therefore provides a reconsideration of social capital and sense of place accounting for the role of emotion with the aim of providing context for the presentation and discussion of the findings. The third section explores the social capital contained within the family. The families of the stroke survivors were the source of affections and loving dispositions but also of tensions and ambivalence. The presence of impairment resulted in the renegotiation of social positions which could lead to the development of guilty dispositions within the stroke survivors, threaten stroke survivors' agency and sense of value within the family. Furthermore, despite the ubiquitous nature of disability within the lives of stroke survivors, talking about and acknowledging the stroke survivors' sense of loss was problematic and could delegitimise the stroke survivor's feelings. The fourth section considers employment based social capital. Within these highly specified social fields, individual's capabilities and competency to fulfil particular roles put their value within such fields under direct scrutiny which produced feelings of anxiety and shame resulting in a devalued identity. The fourth section explores the fallacy of stroke support groups; while holding the potential to be a highly resourceful form of social capital such groups did not appear to meet this potential and neglected to account for shared interest beyond stroke thus failing to

cultivate positive emotional engagement - they fail to meet the needs of the *social libido*. Furthermore, stroke support groups were deemed by some as something to avoid due to a view that those who attend stroke support groups, and stroke survivors more generally, were worthy of pity. This exposed a subtle form of *symbolic violence* and perpetuated devaluing and delegitimising views of disability. Finally implications for research, practice, patient information and support will be discussed.

6.1.2: Interview Sample

Of the 36 individuals invited to take part in an interview 28 responded positively. All 28 who agreed to an interview were met with in person however only 26 interviews were used in analysis; one interviewee was excluded as she was too unwell to participate fully and another believed he had experienced two TIAs as opposed to a stroke.

Table 6.1 provides an outline of age, time since stroke and employment both before and after stroke while Table 6.2 details the interviewee's acquired impairments. It will be clear from these tables that the interviewee sample contains variation in terms of demographics and impairments.

Appendix 6.1[13] provides some basic indicators of social capital from the postal survey. The majority (n=21) had a spouse and therefore were guaranteed day-to-day social interaction. The spouse was, for these interviewees, typically the key source of practical and emotional support. Beyond the spouse (and live-in family members) the

[13] The tables for the social capital indicators and the Social Relationships sub-scale from the BOSS have been placed into the appendices due to their size.

majority also had at least some contact with family. For many this contact was from adult children who typically provided additional practical forms of support such as household chores. Family members also offered emotional support. Contact with friends was much less frequent than contact with family. Friends were also a source of emotional and practical support and often functioned as a source for alternative views. Miranda and Iona were the two key interviewees who had a diverse array of acquaintances beyond family and friends as they were actively involved in clubs and activities. These two interviewees were, however, also bereft of physical or cognitive impairments making maintaining such activities more straight forward as they did not have to rely on others to assist them. A large minority (n=12) of the interviewees provided responses which indicated a reduction of their social contact. For some, such as Frank and Yvonne, this was believed to be related to age as their friends had also experienced forms of bodily deterioration or had passed away. This does indicate that elderly stroke survivors are at greater risk of social isolation due to issues out with their own control or due to their own impairments. Such issues have been stated elsewhere (Boden-Albala *et al.,* 2005). For two interviewees in particular, Victoria and Chris, a reduction in social contact was an overriding theme throughout their interviews and was reflected within the responses provided within their surveys. For Victoria this appeared to have occurred due to her mobility problems and thus lack of physical independence, while for Chris this stemmed from his aphasia and associated difficulties with background noise which made socialising within loud environments problematic. The loss of friends and reduction in social contact is a known potential consequence of stroke (Northcott & Hilari, 2011).

Appendix 6.2 provides the responses from the Social Relationships sub-scale of the BOSS. A majority of interview respondents indicated there had been at least some impact on their social relationships within each scale item, aside from the item on maintaining a role as a friend or family member, where those reporting no impact (n=13) were equal to the numbers reporting at least some impact (n=13). The responses provided to these questions again expose a clear divide between those with few or no impairments, such as Grace, Kelly and Miranda and those with impairments such as Victoria, Chris and Jessica. Those with impairments were more likely to provide responses indicating that social relationships had been problematised by the presence of impairments. Therefore, social relationships, and thus social capital represent a vulnerable resource for stroke survivors, particularly those with more substantial impairments. The qualitative findings presented below aim to unpick why social relationships become, and remain problematic for stroke survivors living in the community in the long-term. It should be noted that all interviewees and other individuals referred during the presentation and discussion of findings have been given pseudonyms and any identifiable information altered to ensure anonymity.

Table 6.1: Interviewee Sample Demographics

	Age	Years Post Stroke	Marital Status	Employment	Employment before Stroke
Victoria	77	3	Married	Retired	Retired
Grace	76	9	Widowed	Retired	Retired
Kelly	71	10	Widowed	Retired	Retired
Miranda	71	11	Widowed	Retired#	Employed (FT)
Caitlin	48	4	Married	Employed (PT)	Employed (FT)
Lauren	67	3	Married	Retired	Housewife
Iona	62	12	Married	Retired	Housewife
Jessica	60	3	Married	Retired	Housewife
Yvonne	84	12	Widowed	Retired	Retired
Eloise	46	11	Married	Unemployed	Unemployed
Shirley	80	3	Widowed	Retired	Retired
Tabitha	68	12	Married	Retired#	Employed (FT)
Martha	76	3	Married	Retired	Retired
Frank	82	3	Married	Retired	Retired
Max	59	3	Married	Employed (PT)	Employed (FT)
Chris	65	11	Married	Semi-Retired*	Employed (FT)
Paul	69	6	Married	Retired #	Employed (FT)
Craig	73	12	Married	Retired #	Employed (FT)
Oliver	69	9	Married	Retired #	Employed (FT)
Albert	75	8	Relationship	Retired	Retired
Greg	60	3	Married	Retired	Retired
Tam	75	3	Widowed	Retired	Retired
Fraser	59	8	Divorced	Unemployed	Unemployed
Callum	58	4	Married	Employed (PT)	Employed (FT)
Kyle	67	10	Married	Retired	Retired
Niall	66	4	Married	Retired #	Employed (FT)

* *Chris had struggled to find work following his stroke and was currently attempting to start his own business*

 # cited their stroke as the reason for taking retirement

Table 6.2: Interviewee Sample: Stroke Acquired Impairments

	Communication	Physical	Memory / Learning	Emotion	Fatigue
Victoria	WRP*	Mobility & Hand Paralysis	Yes	No	Yes
Grace	None	None	No	No	No
Kelly	None	Facial Paralysis *When Tired*	No	No	No
Miranda	None	None	No	No	No
Caitlin	WRP	None	Yes	No	Yes
Lauren	WRP	Mobility & Dysphagia	Yes	Yes	Yes
Iona	None	None	No	No	No
Jessica	None	Mobility & Hand Paralysis	No	No	Yes
Yvonne	None	Mobility	No	No	No
Eloise	WRP	Hand Paralysis	Yes	No	No
Shirley	None	Mobility	No	No	No
Tabitha	None	Mobility	Yes	No	No
Martha	None	Weakness (Left)	No	No	Yes
Frank	Aphasia	Mobility & Balance	No	No	No
Max	WRP	None	Yes	Yes	No
Chris	Aphasia	None	No	No	Yes
Paul	WRP	Mobility, Facial Paralysis & Dysphagia	Yes	No	No
Craig	Aphasia	Mobility	Yes	No	No
Oliver	None	None	Yes	No	No
Albert	None	None	No	No	No
Greg	None	Mobility	No	Yes	Yes
Tam	None	Mobility And Balance	No	No	Yes
Fraser	None	None	No	No	No
Callum	WRP	None	Yes	No	No
Kyle	None	Mobility	No	No	No
Niall	None	Mobility, Balance & Loss of Sensation In Right Hand	No	No	No

* WRP = Word retrieval problems

6.2: THEORETICAL PREAMBLE: SOCIAL CAPITAL & THE ROLE OF EMOTIONS

The theoretically driven thematic analysis required considerable consideration and reconsideration of both data and existing theory. In focusing in on data which related to social capital and social position, the emotional co-dependency within certain social connections as well as emotional experience within social spaces meant that the role of emotion became an appropriate avenue to explore within Bourdieu's work. Therefore, the use of emotion and its role in (re)producing social capital, sense of self in social space and thus embodiment within Bourdieu's work has been presented below as a theoretical preamble to contextualise the findings.

6.2.1: Social Capital: Strategic Social Manoeuvring & Emotional Co-dependency

Social capital, like all forms of capital within Bourdieusian theory, is fundamentally about resource. Social relationships are the basis of social capital yet what makes social relationships form capital is that they enable individuals to gain access to the resources (economic, social and cultural) held by other individuals with the volume and value of those resources being of great importance (Portes, 1998). According to Bourdieu the reproduction of social capital requires an '*unceasing effort … in which recognition is endlessly affirmed and reaffirmed'* (1997 [1986]: 52). For this effort to be profitable however it requires:

> "*…a specific competence (knowledge of genealogical relationships and of real connections and skill at using them, etc.) and an acquired disposition to acquire and maintain this competence*" (*ibid*).

This often leads to the view that for Bourdieu accumulating social relationships, and thus capital, is a matter of strategic and rational social manoeuvring. However, the matters concerning the relationships formed with others are typically more complex. For Bourdieu relationships and networks are the product of *investment strategies* which are undertaken:

> *"…consciously* ***or unconsciously*** *aimed at establishing or reproducing social relationships that are directly usable in the short or long term, i.e., at transforming contingent relations, such as those of neighbourhood, the workplace, or even kinship, into relationships that are at once necessary and elective, implying durable obligations* ***subjectively felt*** *(feelings of gratitude, respect, friendship, etc.) or institutionally guaranteed (rights)"* (1997 [1986]: 42 [emphasis added]).

This excerpt reveals two key issues: firstly the manner in which relationships are negotiated and formed is not always a fully conscious endeavour and secondly social relationships, while produced with an element of strategy, are solidified by obligations

based in emotional connections and / or rights. How social capital is utilised to access resources can be explicit or implicit. In specific social fields based on employment, for example, where networking is a required skill, required precisely for access to valuable resources. In such fields social relationships are often negotiated explicitly with personal or group advantage in mind and these relationships are solidified by rights, obligations and respectful reciprocity. Close, informal social ties such as family and close friends are perhaps not negotiated so explicitly. This is something which Bourdieu gives some consideration to in his discussion of the family. The family is a social construction, a fiction; however it is also a realised category (Bourdieu, 1996) which operates as a structuring structure. Families represent a considerable investment of time, emotions, physical closeness, and the exchange of economic and cultural capital. For the individual the family can embody a particular kind of social capital heavy with emotions and a deeply woven shared history. In many ways the family represent ties that bind, a cohesive social capital as Bourdieu states:

> *"…the family is the product of a labour of institutionalization, both ritual and technical, aimed at durably instituting in each member … feelings that will tend to ensure the integration that is the condition of the existence and persistence of the unit… a united integrated entity which is therefore stable constant…"* (Bourdieu 1996: 22).

Bourdieu goes on to explain that the family unit requires '*countless acts of reaffirmation and reinforcement'* that produce '*obliged affections and affective*

obligations' (*ibid*). Within the family unit pedagogic action and mutual practical and emotional service '*sanctioned and memorialised*' by family photographs and other mementos, transform these obligations to what Bourdieu calls *loving dispositions* (*ibid*). These arguments can be extended to include close friendships which also require reaffirmation and reinforcement resulting in affecutal obligations. As emotions and a sense of obligation are typically at the root of such relationships, the manner in which these relationships are negotiated can see rational, strategic manoeuvring suspended, fogged by emotional concerns of love, friendship and so on. In this sense the social capital of close ties can be viewed as based in emotional co-dependence. This differs somewhat from formal networks, particularly within the world of work where relationships are often based on usefulness and advantage.

However, the emotions which underpin family relationships are not always positive and nurturing; emotional co-dependence can also lead to quarrels, conflict and interpersonal stress (Widmer, 1999). Conflict and stress are as much a part of the family as love and obligation. The presence of acquired disability can result in an increased demand for caring emotions and affectual support between family members but also produce *'irrational emotions'* or '*shameful thoughts and feelings'* of '*intense anger'* (Rolland, 1999: 246). In order to maintain itself the family must always attempt to counteract such '*forces of fission'* with the '*forces of fusion'* (Bourdieu, 1996: 22) however, as will be examined below the forces of fusion, that is, affectual obligations and loving dispositions, can themselves create considerable tensions within the families of stroke survivors.

While the focus of this discussion has been on family it is not to say that emotions are absent within social capital beyond family. Bourdieu muses that:

> "*… sense of one's place, and the affinities of habitus experienced as sympathy or antipathy, are at the basis of all forms of co-optation, friendships, love affairs, marriages, associations, and so on"* (1989: 17).

Therefore, all forms of social capital and sense of social position become characterised by positive or negative emotional experience which become embodied within the habitus. However this chapter argues that what is missing from this analysis is the potential for one's sense of place and negotiation of social capital to be experienced as *ambivalence* rather than a uniform sympathy or antipathy.

6.2.2: Emotions as Dispositions

Bourdieu has been accused of not fully realising the role of emotion within his extensive body of work. This is something which Reay (2000, 2004) has highlighted and attempted to tackle by presenting emotions as a key form of capital. According to Reay:

> *"[e]motional capital is generally confined within the bounds of affective relationships of family and friends and encompasses the emotional resources you hand on to those you care about"* (2004: 60).

Viewing our emotions as capital is a potentially useful approach and perhaps the emotions of others can also be viewed as capital which can be used for advancement. As Wacquant explains a capital is:

> "*… any resource effective in a structured arena of social action (field) that allows one to obtain specific profits that arise out of activity and contest within that arena*" (1998: 26).

However, while individuals can gain from the emotions of others and their own emotion-work can be passed on to others, conceptualising emotions as capital is potentially problematic. This is because emotions themselves underpin social practises in a manner which is not necessarily rationalisable to the degree of capital, particularly within close ties. Viewing emotion as capital perhaps ignores its subtleties.

Emotions are possibly best viewed in two key ways. Firstly, emotions fundamentally underpin the (re)production of social capital and therefore can be viewed as a crucial element of the negotiation of social capital as opposed to a form of capital in and of itself. Bringing emotions to the fore within analysis of social capital, particularly within family based social capital, has the potential to expose the affectual resources gained from social capital and also why close ties can prove resilient while being laced with tensions. Secondly, and relatedly, emotions can be viewed, in perhaps their truest form, as dispositions. This is hinted at in Bourdieu's definition of the bodily hexis:

> "*...a political mythology realized, embodied, turned into a permanent disposition, a durable manner of standing, speaking, and* ***thereby of feeling and thinking***" (1990: 69-70 [emphasis added]).

The ways in which the dispositions responsible for varying emotional reactions are instilled within the body are, to a degree, outside of the conscious will of the individual (Reed-Danahay, 2004). Individuals are taught appropriate emotional responses from childhood and these learned dispositions inform behaviour and action and these dispositions will evolve over time through varying social experiences. Emotions, like other dispositions are both conscious and pre-conscious; they involve culturally informed *understanding* but are inculcated through social practices and experiences. Bourdieu goes further, emotions are not merely conscious and pre-conscious reactions but also interwoven with the process of (re)producing domination:

> "*the dominated, often unwittingly, sometimes unwillingly, contribute to their own domination by tacitly accepting the limits imposed, often take the form of bodily emotions – shame, humiliation, timidity, anxiety, guilt – or passions and sentiments – love, admiration, respect*" (2001: 38 [cited in Reed-Danahay 2004: 102]).

Our feelings towards our situation and towards others can impose limits and these are not something which can necessarily be overcome by conscious will due to the deep-seated embodiment of emotional response. This is of particular importance for this study. Becoming disabled or experiencing chronic illness can evoke feelings of shame,

guilt and embarrassment due to the impairments themselves, the practices demanded by the disability or illness, or due to societal perceptions which surround the cause of the illness (Scrambler, 2009; Olsson, Lyon, Hörnell, *et al.,* 2009; Chapple, Ziebland & McPherson, 2004). Such emotions can impact upon behaviour and self-perception. Both bodily emotions and sentiments can influence the individual's competency at negotiating their social capital and can also disrupt their sense of social position or status. Emotions inform action but can also disrupt it and problematise it. For Bourdieu our bodies reveal the '*deepest dispositions of the habitus'* yet bodily management, posturing, gesture and so on are inherently emotion laden in both explicit and implicit ways. A heavy sigh as a response, for example, can explicitly indicate sadness, anger or apathy depending on the subtleties of delivery and thus expresses, wordlessly, how an individual feels about an issue. These small bodily acts, in their own minor ways reveal attitudes, values and background and also simply how a person is feeling at that specific time, in that specific context. The body can also betray how the individual, rationally, wishes to be perceived by others within particular contexts due the subtle simmering emotions they can reveal; blushing with embarrassment or nerves, trembling with anger or fear or even the subtle quivering of the lips as one attempts to hold back an 'inappropriate' laugh. Therefore, emotions are not necessarily rational. It is useful here to consider, momentarily, Judith Butler's examination of emotion and its role in relationships:

> *"… grief displays the way in which we are in the thrall of our relations with others that we cannot always recount or explain, that often interrupts the self-conscious account of ourselves we might try to provide in ways that challenge the very notion of us as autonomous and in control … We're*

> *undone by each other … To be ecstatic means, literally, to be outside oneself, and this can have several meanings: to be transported beyond oneself by a passion, but also to be beside oneself with rage or grief … I am speaking to those of us who are living in certain ways beside ourselves, whether it is in sexual passion, or emotional grief, or political rage"* (2004: 19-20).

For Butler, as individuals we are tied with others in ways that can destabilise our imagined sense of personally bound, autonomous self-hood. Our emotions, while at the core of the self, can also threaten identity in that emotions can compromise and betray the rational self, impeding clarity of action or practice. Positive and negative emotional experience can and will impact deeply on the individual's sense of self, and perception of their selves in the eyes of others as well as their capacity for action. Emotions underpin actions and interactions; emotions are at the heart of dispositions and therefore emotional responses are vital to the *embodiment* of social interaction in the habitus. As such emotional responses to stroke acquired impairments and disability have the potential to impact upon socio-spatial encounters and thus can threaten a stroke survivors' competency to negotiate their social capital.

6.2.3: Meaning & Social Relations: The Role of the Illusio

A final aspect of emotions which underpin social capital and social interactions is the role of emotions in the '*illusio*'. According to Bourdieu illusio represents '*the fact of being caught up in and by the game, of believing that … playing it is worth the effort*' (1998: 76). However, as Hage argues the illusio also represents:

> "*… the way we invest and attach ourselves to those elements of the social world that give our lives meaning whether it is our job, our personal relations, our reputation, our hobbies or our ideals … Bourdieu links the illusio with a social libido because the way we invest ourselves in the social world is not only intellectual but libidinal* (2010: 140) … *illusio which denotes a self that invests itself emotionally and libidinally in what is likely to make life meaningful"* (2009: 66)

This speaks to the manner in which social position can give meaning to lives. It also hints at the process whereby libidinal feelings towards hobbies and activities provide individuals with a sense of meaning which can solidify relationships to others with whom such hobbies and activities are shared. In this sense cultural capital and social capital (and physical capital) become both themselves interwoven and interwoven with emotions and meaning. Therefore, while family social capital can be solidified by loving dispositions, other forms of social capital are not only solidified by rights, like work based social capital, but also by shared *joy* of, and meaning gain from, a particular activity or hobby. Disability can detach individuals from employment or an activity. This can remove the meaning and joy produced by the activity and also threatens the social capital interwoven within these activities.

6.2.4: Discussion Summary

In summary, emotions, as well as sentiments, meaning and rights underpin the (re)production of social capital, social interactions and thus socio-spatial position. Due to the role of emotion, negotiating social capital (particularly within family based relationships) is not always fully rational or fully conscious. Furthermore, an individual's ability to be rational can be compromised by the emotional experience within socio-spatial encounters. As will be discussed below the impairments thrust upon stroke survivors' could result in these encounters becoming characterised by ambivalence and competence at negotiating social capital could be compromised by emotions. Within this chapter it will be argued that the emotions underpinning social interaction between the stroke survivors and their social connections played a crucial role in the embodiment of an ambivalent or devalued sense of self.

6.3: AFFECTIONS & TENSIONS

6.3.1: Obliged Affections & Affective Obligations

The vast majority of discussion around social capital within the interviews was anchored on family ties and the support they provided. Family support, which is known to contribute to positive functional recovery and psychological well-being post- stroke (Kwakkel, Wagenaar, Kollen, *et al.,* 1996; Palmer & Glass, 2003), is typically the main source of support and assistance for people with disability and chronic illness. A stroke and accompanying disability represent '*an organic, literally embodied fact'* (King 1993: 72). This ultimately means that even the most banal of daily tasks, formerly taken for granted, become fully conscious social acts. The practical support provided by family members thus became an unavoidable reality of existence from assistance putting on a

pair of socks and shopping to personally intrusive assistance such as help with toileting and bathing. Such acts of support were deemed essential:

> **Martha**: *The three girls [daughters] … and the two boys [sons] …* ***I don't know what I would have done without them****… one does the cleaning… and the big [supermarket] shop…*

These acts of *affectual obligation* could be the difference between survival and struggle for daily living within the home and access to the world beyond the home. The stroke survivors where acutely aware of the support they received and were grateful for it:

> **Yvonne:** *…the eldest one [child] lives in England. The other three are in [local town]. So I get looked after… I'm well looked after … My grandson … is very helpful. I call him my wizard… he comes and gives me lunch and he comes back at tea time to see if everything is okay … so I have one grandson who is very attentive.*

Being cared for by family members creates *sympathetic* social interactions. Such interactions can instil a sense of being of value, of being worth the time effort of being cared for and could even increase the cohesion of family relationships:

Max: *[things have] strengthened I suppose with my wife… my wife [has been] important, very important*.

Greg: *My wife is the most important person in my life in so far as she has now become almost a carer… we've definitely become closer*

However, while families proved to be resilient, sympathetic and loving in response to the presence of impairments the alterations within the social roles presented considerable tensions as discussed below.

6.3.2: Renegotiating the Game: Ambivalent Sense of Place in Social Space

Habitus provides individuals with a *'feel for the game'* (Bourdieu, 1998: 80) and *'implies a "sense of one's place" but also a "sense of the place of others"* (Bourdieu, 1989: 19) within social fields. In her analysis of the impact of AIDS dementia onset and diagnosis on significant others Kelly utilises the notion of losing the feel for the game and concludes that significant others no longer knew '*what to expect of their loved one or how to behave in relationship to him or her*' (2010: 432) as they could no longer rely on '*previous familiar and familial patterns of relating'* (2010: 434). Therefore, new ways of relating had to be found. Kelly's elucidations are relevant here as alterations of sense of place in social space were evident within this study:

Paul's Wife*: …Paul would do all the stuff outside and in the garden*

Paul: *Anything electrical and that...*

Paul's Wife: *and bank things, national insurance, income tax. Paul did all that, now I do it.*

Interviewer*: Has this changed … the way you two interact?*

Paul's Wife*: Yes, I was never so voiceful as I am now, but I didn't have to be and as I say to Paul, I'm not trying to pick him up when he's wrong [but] it's important for things he forgets.*

Paul: [pauses and sighs] *I have to live with it you know? I have to accept it… It's something you've got to live with I'm afraid.*

Impairments and disability can mean that stroke survivors are no longer able to take care of the chores which they previously had. This typically results in wives, husbands or children taking over these chores and tasks. A change in the stroke survivor's body necessitates a change in a family member's behaviour. This, in turn, can alter how they interact. Stroke survivors and their families typically have the world of illness and disability thrust upon them without a '*psycho-social map'* (Rolland, 1999: 242) to guide them. The stroke presents a fundamental *game* changer. In order to maintain the family unit family members must alter their behaviour to accommodate and support the stroke survivors' impairments, counteracting '*forces of fission'* with the '*forces of fusion'*. In the example above Paul's wife took on her husband's role which appeared to result in her becoming more dominant within the relationship; new *patterns of relating* had evolved out of the couples' experience of living with Paul's impairments and new dispositions had been formed. Role changes were not free of tensions however; Paul's statement *I have to live with it you know? I have to accept it…* was uttered under strained tones. These strained tones subtly expose the ambivalence experienced regarding role or position changes. While stroke survivors were

appreciative of the extra work required of, and support given by family members, they could also be frustrated at playing witness to other's absorption of their daily tasks:

> **Jessica**: … *he's [husband] taken over my role that I had. He looks after the house, does the washing, the cooking … the shopping … he's got that [arrangement of ornaments on the windowsill] all wrong, he's obviously been cleaning, dusting and the whole thing - I just want it all off there coz it's just not right … As you can see I've got quite a big garden. I used to do all of this myself. This was my passion. I've laid everything out, my husband's maintaining it at the moment but I laid it, I dug all these borders. Dug them all out and planted. I did that all myself so that is* ***my*** *garden… it's a big frustration…*

In the excerpt above Jessica's ability to fulfil her role as housewife was problematised by her impairments. As mentioned within the introductory discussion the *illusio* represents a self that *invests itself emotionally and libidinally in what is likely to make life meaningful* (Hage, 2009: 66). The meaning invested in social roles such as breadwinner or housewife/husband emotionally embeds individuals within the social world around them. The social role, the ability to engage in meaningful activities provided by that role, and thus the value attributed to that role can be swept away by acquired disability, rupturing the embodied sense of self in social space. Because the stroke survivors not only lost social roles, but also watched while others took over their roles, the stroke survivors could become frustrated not only at their situation but

at their family members. The sympathy embedded with the acts of family members can thus become embodied as ambivalence within the stroke survivor.

6.3.3: The Embodiment of Guilt

Caregiver burden is a phenomenon which has been widely researched (Reimer *et al.,* 1998; Han & Haley, 1999) and related to this stroke survivors have reported anxieties regarding becoming a burden (Dowswel, Lawler, Dowswell, *et al.,* 2000; Lynch, Butt, Heinemann, *et al.,* 2008; Wood, Connelly, Maly, 2010; Erikson, Park & Tham, 2010). The threat of being perceived as, or feeling like a burden was a common concern for the stroke survivors within this study. Many perceived accommodating their bodies in social spaces within and out with the home negatively as '*a hassle'* or '*a bother*' for others, as Greg stated:

> *'I hate it if I have to shout to her [wife], it's like summoning a servant. I don't like that but some day's I've got no option. She doesn't mind, but I feel it'.*

Feelings of guilt and fears of becoming a burden could have a direct impact on the stroke survivors who would sometimes opt to restrict what they asked of family members in order to prevent becoming a burden. The excerpt below illuminates these tensions:

Victoria: *I feel as though my social life has shrunk to my family… I can't go anywhere unless [my husband] takes me.* ***I feel that I am impinging on him****…. There is an art society in [town], but if I joined that, I've been asked if I want to join it. If I joined it I'd have to get him to go down there and come back home and come down again to pick me up.*

Interviewer: *Do you not think he would be happy to do that?*

Victoria: *Yes he would. I would just feel [sighs]* ***I would feel guilty****…*

Engaging in arts and crafts reflects the *illusio* and *social libido*. Many of the stroke survivors discussed such meaningful activities and the importance of these to their lives yet, like Victoria, often depended upon family members to engage in such activities on a social level. However, despite the importance of such activities and the opportunity such activities present for (re)producing social capital outside the home, stroke survivors would often choose to opt out if they felt this would burden their family. This reflects how the stroke survivors own affections and loving dispositions towards family members and the embodiment of guilt, a guilty disposition, can prevent stroke survivors from utilising their family based social capital for their own advantage; it compromises their *competency* at using their social capital. In this sense social manoeuvring can become fogged by emotion, exposing that the process of negotiating close ties is not through strategic and rational practice but though affectual obligations based on emotional co-dependency.

6.3.4: Support, Domination & Agency

Carers and family members of stroke survivors can become over protective which has been known to lead to stroke survivors becoming dependent, promoting poor motivation (Glass & Maddox, 1992; Kvigne *et al.,* 2004). However, over-protective or controlling behaviours from family members also present a threat to agency and create a dominant and dominated social hierarchy. The actions, wants and wishes of the interviewees were often scrutinised and supervised by their family members who ultimately judged whether certain actions were appropriate, or safe. The impact of over-protective behaviour was typified by Jessica's example below:

> **Jessica***: He's [son-in-law] just very supportive, like when I go around to their house you know, he always … cooks me a nice meal … he always brings me a wee glass of wine. I'm never sure if I should really have one or not but you know … coz when I'm here [home] it's always "no you can't get any, you've got to get up the stairs" and I'm always "but one won't hurt me"…That's one and two, husband and daughter, they're looking after my welfare.*
>
> **Interviewer***: So is he a little naughty then? In terms of what he allows you to get away with – it that how you'd put it?*
>
> **Jessica***: [pause] No, I won't say that, he's just quite understanding, quite perceptive. He's quite an intelligent bloke you know and [daughter] she rushes to do things for me sometimes…*
>
> **Interviewer***: hmm, so he maybe gives you more room to be yourself?*
>
> **Jessica***: YES! Yes.*

This excerpt reveals a considerable amount about the potential for caring behaviour to shift from caring to domineering. Family members take on a dominant position as able bodied carers who, out of affectual obligations, make decisions regarding the disabled person's health. Health is used here to legitimise the family member's denial of the stroke survivor's specific want. However, as the stroke survivor knows these acts are a reflection of love and affection, undertaken to protect their welfare, they are powerless to argue. Thus the stroke survivor's health becomes a symbolic 'trump card'. This exposes a subtle emotion laden *symbolic power*; the implicit semiconscious rules of social domination which occur within day-to-day social interaction maintaining a social hierarchy. Thus stroke survivors can *unwittingly* contribute to their own domination *by tacitly accepting the limits imposed* upon them due to the emotional co-dependency underpinning family social capital.

What is most problematic is that these individuals are adults who, prior to their stroke, were the guardians of their own bodies and health. Due to the stroke event the stroke survivor's body and health become a family concern with the stroke survivor's behaviours being open for question. The body is a vital element of social experience and the instrument through which agency and structure are ratified. However, once the body becomes controlled by another or others the individual's ability to utilise their body as an instrument of agency becomes threatened. Furthermore, within these daily encounters, in which a family member dictates whether the stroke survivor can or cannot take part in something, do something or consume something, that individual's identity is diminished to their stroke; to their unhealthy body. In the excerpt above Jessica's enthusiastic agreement that her son-in-law's actions let her 'be

herself' reflects the frustration in a process whereby the individual becomes superseded by their health condition. According to Sewell social resources can assist individuals in obtaining, maintaining, or producing power in social relationships and agency implies the ability to exercise some control over '*the social relations in which one is enmeshed*' (1992: 20). Acts of care, which are ultimately underpinned by well-meaning intent, can remove the individual's ability to exert control, diminish the individual's *competence* at utilising his or her social capital and thus threaten the individual's agency. Once more the stroke survivors' experience of such social interactions becomes characterised by ambivalence; sympathetic yet unsympathetic.

6.3.5: Acknowledging Disability: The Role Shame & Embarrassment

At the very centre of Bourdieusian theory is a concern with the body as a bearer of symbolic value (Shilling, 1993). The body represents physical capital and is thus a possessor of power and status, and is therefore fundamental to the accumulation of various resources. The symbolic value of disabled bodies is problematic due to their apparent lack of physical capital and due to the societal representations of disablement '*which often renders the disabled body as broken, incompetent, powerless, and dependent*' (Edwards & Imrie, 2003: 252). As individuals embedded within a society which can stereotype and demean disabled bodies this negative view will have formed part of the cultural encoding of the habitus of both stroke survivors and their families. The stroke survivors themselves expressed embarrassment, or shame, and disquiet regarding their bodily status, for instance Lauren remarked '*I'm* ***just*** *a cripple'* and Tabitha stated, '*even looking in the mirror I don't see me … I don't like myself*'.

These emotions expose an embodiment of shame, and reinforce the devalued identity placed upon disabled bodies with the cultural milieu. This can be viewed as symbolic violence and thus the stroke survivors are, in a sense, contributing to the marginalisation of disabled people, their social position and bodies. This disquiet and sense of shame towards their bodies and altered status impacted upon the negotiation of their social capital. Some discussed hiding their disabilities from family members, particularly from their children as Greg stated:

> ... *whenever we go and visit [my son] I'm always upbeat, doing the best I can trying not to let it show*.

These acts further reveal an embodied sense of shame and expose the lengths individuals can go to in order to avoid being connected with the negative connotations associated with disability. To acknowledge the presence of disability opens the body, and the self, up to the speculation, concern and pity of others who may question the individual's competency and capability. This sense of shame regarding identifying as disabled was also reflected, in one instance, in the actions of family members as Jessica discussed:

> *… even if I say something now like "oh I'm disabled", he'll say "no you're not disabled" you know? He still won't accept it.*

While this was the only instance where a stroke survivor mentioned a family member refusing to acknowledge disability it does suggest that it is not only stroke survivors themselves who distance themselves from the tag of disability. The processes through

which individuals become to 'know their place', that is to become (semi)consciously aware of their approximate value and legitimacy within a social field, can be explicit through material assets and the inclusion within or exclusion from social spaces. However this process can also be somewhat implicit as Bourdieu explains:

> *"[t]here is every reason to think that the factors which are most influential in the formation of the habitus are transmitted without passing through language and consciousness, but through suggestions inscribed in the most apparently insignificant aspects of things, situations and practices of everyday life. Thus the modalities of practices, the ways of looking, sitting, standing, keeping silent, or even of speaking ('reproachful looks' or 'tones', 'disapproving glances' and so on) are full of injunctions that are powerful and hard to resist precisely because they are silent and insidious, insistent and insinuating"* (1991: 51).

It is not untypical for those with disabilities to experience being ignored, spoken over, stared at or being the cause of a non-disabled persons discomfort and anxiety (Baxter, 1989; Morris, 1991; Shiling, 1993; Phemister & Crew, 2012). There are also common place derogatory terms within the English language which are used against disabled or impaired individuals or to offend non-disabled people within society such as *'freak', 'gimp', 'spastic', 'spaz', 'cripple', 'cretin'* and '*retard*' (Russell 1998: 14). These are pointed examples of the *insidious, insistent and insinuating* forms of othering of people with impairments and disabilities. Politically correct terms such as disabled can

suffer being perceived as a polite proxy for these pejorative terms and thus the negative inferences associated with them. As Linton states, '*the term disability is a linchpin in a complex web of social ideals*' (1998: 10 [cited in Gordon & Rosenblum 2001]). As such disability is a term typically loaded with negative symbolic value; one to be avoided.

6.3.6: (De)legitimising Grief & Loss

The previous section discussed the role of shame and guilt regarding impairments and the role this plays in reaffirming negative connotations regarding disability. The concern here is a different set of emotions; grief and loss. While shame and embarrassment reflect the embodiment of the negativities of disabled status within the cultural milieu, grief and loss are considerably more personal; it is not about outside perception *as much as* personal feeling.

As discussed at the outset of this thesis the evidence that disability is life changing and can constitute loss is considerable. Acquiring a disability results in the *'erstwhile taken-for-granted world of everyday life'* becoming *'a burden of conscious and deliberate action'* (Bury, 1982: 176). People living with chronic illness and disability may struggle to absorb their altered health status with their personal life histories resulting in 'chronic sorrow' (Ahlström, 2004). Indeed, depressive symptoms are common among stroke survivors with depression occurring in one third (Knapp, & House, 2010; Broomfield, Laidlaw, Hickabottom *et al.,* 2011). This does not mean that living with chronic illness and disability automatically equates to a never ending personal

torment; happiness can be experienced despite the presence of illness and disability (Albrecht & Devlieger, 1999; Meyers, 2000) and this was present within the interviewee sample. However it does highlight how difficult living with impairments can be and thus the legitimacy of feeling loss or grief as Morris states:

> *"… our grief is not a "failure to come to terms" with disability. Our dissatisfaction with our lives is not a personality defect but a sane response*…' and all too often there is a denial of *'the personal experience of physical and mental restrictions, of illness, of the fear of dying"* (1991: 9, 10).

Having someone to talk to regarding such feelings represents an important resource to offset negative feelings regarding the self. Emotionally supportive interactions, attentive listening, and reassurance can promote a feeling of acceptance, being cared for, and valued in spite of overwhelming personal problems as illuminated here:

> **Caitlin**: *My daughter's very close to me, all my kids are, but especially my daughter. If I get upset she listens to me. So does my husband, my husband's really good but she listens to me…*

Such emotion-work or '*constant maintenance work*' is fundamental to the perpetuation of a '*family feeling*' and '*loving dispositions*' (Bourdieu, 1996: 22) and therefore essential to the operation and preservation of family based social capital.

The provision of emotional support, of listening and talking, solidify the individual's sense of space and place within the family and the co-operation between family members becomes endowed in *sympathy* which enables the family unit to be resilient. The act of listening legitimises the stroke survivor and the stroke survivors' feelings regarding his or her disability and their right to hold such feelings; his or her opinions and feelings are valid, worth hearing and he or she is worth listening to, and ultimately he or she is of *value*.

While the family is solidified in countless acts, affective obligations and obliged affections, love and sympathy - sympathetic listening appeared to have its limits. Some family members would listen but ultimately tell the stroke survivor to accept their situation and to 'snap out of it':

> **Greg**: …*she [wife] very definitely says 'snap out of it, it's in the past, except the way things are now 'coz you're still here blab la'. I find it very hard to accept that. I find it very hard to accept some of the things I can't do anymore. It's not good, the way I am at the moment but as everyone says it's better than the alternative. As my wife says 'look, you've been left with a bit of a slight limp, you can't walk as fast as you used to, so what? That's nothing, you're 61 years old, accept it…*

Being told to 'snap out of it' is understandable. Disability is lived and lived with - to quote from Milan Kundera's *The Unbearable Lightness of Being*:

> *"[n]ot even one's own pain weighs so heavy as the pain one feels with someone, for someone, a pain intensified by the imagination and prolonged by a hundred echoes*" (1999: 31).

Disability is omnipresent within the lives of disabled people and within the lives of their family as demonstrated by the phenomenon of caregiver burden. Caregivers are often the source of both physical and emotional support. Listening to tales of sorrow can be as burdensome as helping someone dress and go to the toilet. It is no surprise that caregivers are also at risk of anxiety and depression (Denno *et al.,* 2013). Furthermore, the lives of caregivers can also be fundamentally changed by stroke, as Lawrence and Kinn state:

> *"[t]he sudden and devastating impact of stroke on family members [can cause] a shift in family members' understanding of their place in the world, of their taken-for-granted understanding of their familiar, pre-stroke way of being"* (2013: 594).

However, as understandable as this response can be it is also problematic as it delegitimises and undermines the stroke survivors' experience of loss and dysphoria. Furthermore, if it is accepted that emotions are pre-conscious and can be beyond the control of conscious will, being told to 'snap out of it' or to 'get over it' is challenging as it suggests such feelings are a matter of choice and can be simply controlled. This

reveals an *antipathy* towards that individual's emotions and a subtle trivialisation of impairments and lost capabilities. This denies the stroke survivor the right to feel sorrowful sometimes and renders such interactions as ambivalent as opposed to sympathetic experiences; the family member offers a sympathetic ear yet essentially does not want to accept and recognise the on-going validity of these negative emotions. While the individual is not necessarily devalued, his or her right to grieve *is*. This notion of grief not being validated has some parallels with Doka's concept of '*disenfranchised grief*' which occurs when a substantial loss is not '*openly acknowledged, socially validated, or publicly mourned*' (2008: 224). This creates a tension which implies that, because the stroke survivor has survived and his or her impairments could be 'worse' their right to their feelings is illegitimate. This tension can be embodied, laid down within the stroke survivors' habitus as dispositions characterised with ambivalence regarding expressing negative feelings about their impairments within the company of their family. This sense of ambivalence has the potential to extend towards their impairments and by extension themselves as their sense of loss is not validated within social interaction. Ultimately being able to come to terms with the loss of bodily capabilities becomes highly tenuous.

Underlying attempts to discuss disability and acknowledge loss with family members is an issue of understanding and appreciation. Individuals who inhabit a shared social space will have analogous habituses; comparable in certain respects yet also distinct. This is because these individuals interact, reciprocally influencing each another and each other's individual habitus. This is particularly so within families where interaction is enmeshed within shared history within a particular kind of shared space which is

'private' and '*backstage … with its door closed to protect its intimacy separated from the external world by the symbolic barrier of the threshold*' (Bourdieu, 1996: 20). Therefore family members often develop an innate understanding and appreciation of each other because they share space and have, to a degree, embodied each other within their respective habituses. It is typically behind this symbolic threshold that personal achievements are most lovingly celebrated and failures and worries are sympathised with. Thus it is within families that our emotions are most capable of undermining our sense of autonomous self-hood, breaking down the barriers of the fleshy body uniting us with our loved ones. Yet, the experience of becoming disabled, being physically or mentally disconnected from previous roles, from valued activities, from the physical and social spaces once accessed freely and of bearing the cultural weight of disability represents a fundamental breakdown in understanding between the able-bodied carer and the disabled stroke survivor. Family members can sympathise with and listen to the stroke survivors' concerns but cannot truly understand the lived experience of disability. Having access to those who have undergone a similar experience can offer a level of understanding and appreciation which can be missing between the disabled stroke survivor and the able bodied family member. Caitlin, for example had made friends during her time in rehabilitation with whom she had stayed in touch:

> **Caitlin**: *I think it is because I can just be me with them, I don't need to be somebody else because they know 'coz they've had it as well. We don't, well I mean we do talk about what happened to us but I don't have to put a face on for them … actually we don't about the stroke, we talk about the*

lives we used to have, we talk about things like that rather than what happened to us.

Family members' lack of understanding regarding becoming a disabled person and the delegitimisation of the disabled persons' negative feelings can instil a sense of not being able to be 'yourself' with family members, of being different, of being 'other'. Those who have undergone similar changes can provide an antidote to this. While such acquaintances do not replace familial closeness, the shared experience of stroke and of the loss of a former way of life is not only sympathised with but is understood and legitimised in a manner that is not fully possible within family interactions.

6.4: NEGOTIATING SOCIAL CAPITAL IN THE SOCIO-SPATIAL FIELD OF WORK: STATUS & SYMBOLIC VIOLENCE

Unemployment following stroke has been associated with financial difficulties, social isolation, low self-efficacy and restrictions on leisure activities (Wilz & Soellner 2009). In turn, returning to work has been linked to psycho-social benefits such as increased financial independence, participation in society, social inclusion, well-being, self-worth and sense of self (Wozniak & Kittner, 2002; Corr & Wilmer, 2003; Hillman & Chapparo, 2002; Gilworth *et al.,* 2009; Medin Barajas, & Ekberg, 2006; Vestling *et al.,* 2003; Lock *et al.,* 2005). According to Edwards and Imrie:

"… the inability to work, and hence to gain value from the exchange of physical capital, is a feature of many disabled people's lives, marking them

> *out as less than equal compared to their able-bodied counterparts"* (2003: 246)

This sense of value attached to employment and thus loss of value or status when employment was not attainable was reflected within the interviews:

> **Callum:** *I needed that [to go back to work] if you see work defining you, I needed to know what my definition was … so I got back to work as quickly as possible.*

> **Chris**: … *I was a valued person, the breadwinner in the family… But now I'm different, I'm a second class person… I felt that when I went to this reunion with my school people, I felt that there because a lot of them, doing brilliant, all got good jobs and all talking about it, and I didn't have much to say, I couldn't claim to know these things, you know I felt my status had gone.*

The statements above also expose the role of employment in igniting the social libido; employment is thus endowed with meaning and social identity. However, retaining or gaining employment can be challenging for those who have experienced a stroke. Chronic fatigue, Loss of concentration, trouble multi-tasking, communication impairments, and irritability are common impairment based hindrances to successful return to work (RTW) (Corr & Wilmer, 2003; Gilworth *et al.,* 2009; Treger *et al.,* 2007). Further identified obstacles to RTW are the dearth of accessible and clear guidance to assist the process (Gilworth *et al.,* 2009). Furthermore, those who do RTW may find work stressful. Pace of work, responsibilities, attitudes of employers and hours of work

are all potential hindrances to maintaining employment post stroke (Alaszewski *et al.,* 2007; *Different Strokes,* 2002). The findings from this study are in keeping with the literature:

> **Callum**: *I took on a new role … and I thought I'd be able to cope with it, but I just can't – I couldn't. It got to the extent where I'd be [going] to see my doctor regularly … I had to resign from the job*

> **Caitlin**: *… you're straight into the work and it's quite noisy. I don't pick up it all now, my brain doesn't. If my manager comes to say to me and it's noisy or people are having a laugh [talking loudly and jovially] it doesn't filter through the same as it would before and then I'm like 'sorry what were you saying' … she knows I'm not as quick as I was and I think she gets annoyed with me sometimes because I'm not picking it up and I say to her "I've been here three years now and I'm three years slower than what I would have been" do you know what I mean? …and I'm afraid to go and ask her again because she might think I'm stupid.*

As the interviewee's accounts of work highlight, impairments, loss of confidence and also the nature of socio-spatial fields all play a role in either hindering or facilitating their ability to maintain employment. Socio-spatial fields are a network of relations of power as individuals struggle for control of capital and thus value. Fields of employment are heightened sights of such struggles where disabled bodies disrupt '*accepted notions of embodied employment*' (Hall, 1999: 146 [cited in Edwards & Imrie 2003]). Manoeuvring within fields which are based on able-bodied assumptions

presents problems of accommodation and understanding. Within such fields people with disabilities become the dominated by default and by the ingrained ableist practices of fields of employment. As mentioned above the dominated typically inadvertently underwrite their own domination by implicitly accepting the restrictions imposed upon them in the form of '*bodily emotions – shame, humiliation, timidity, anxiety, guilt* (Bourdieu, 2001: 38 [cited in Reed-Danahay 2004: 102]). Chris' sense of lost status and Caitlin's fear of being thought of as stupid represent a tactic acceptance of their devalued and dominated position and are ultimately forms of symbolic violence.

6.5: STROKE SUPPORT GROUPS & SOCIAL COMPARISONS

6.5.1: Stroke Support Groups: A Fallacy?

Social capital is a resource which is based on mutual advantage but can also be based on commonalities. According to Bourdieu and Wacquant:

> "...*when habitus encounters a social world of which it is the product, it is like a 'fish in water': it does not feel the weight of the water and it takes the world about itself for granted*" (1992: 127).

This is in part due to an affinity with the rules of practice within that social space and also due to, at least some level of commonality with the other individuals that occupy that field or position within that field:

> "*[i]ndividuals who occupy similar social positions the proximity of conditions, and therefore of dispositions, tends to be translated into durable linkages and grouping"* (Bourdieu, 1984: 730)[14].

A commonality or affinity with others can stimulate the formulation of social and socio-political groups, which can be viewed as social capital existing within specified social fields. These groups typically come together in order to share a specific interest or to highlight a political issue. Stroke support groups have the potential to represent such a coming together and as such have the potential to form a specified form of social capital. Caitlin's experience with the friends she made within rehabilitation, mentioned above, shows that talking with fellow stroke survivors can be of value. Furthermore, community based stroke support groups have been found to be beneficial (Weltermann *et al.,* 2000) however peer support groups can suffer negative outcomes such as conflict, criticism, emotional over-involvement, reinforcement of harmful behaviours, and weakened self-efficacy (Dennis, 2003; Hoey *et al.,* 2008). Within this study stroke support groups did appear to fall short of the mark:

> **Shirley**: … *it's [stroke support group] not for me because… I need something to stimulate me… bingo, bingo, that's all they think about. Well, what does that do to the mind?*

> **Lauren:** *But we [the stroke group] don't talk about it. Just a cuppa tea.*

[14] This speaks to the notion of individual's having a similar habitus to others within the same social group or class. It should of course be stressed that '*no two individual habituses are identical*' (Bourdieu 1990: 46).

> **Lauren's Daughter:** *She wants to get her feelings out about the stroke but they don't talk about it*

Both of these comments reveal that informal stroke support groups can fail to provide an effective resource. Rather than an exchange of ideas and supporting each other in regard to their experience of stroke, these groups were often merely a coming together of individuals, who happened to have had a stroke. For Shirley, bingo did not interest her and for Lauren the support she wanted from the group failed to materialise. These social connections therefore failed to effectively form capital. This is because the mere fact of having a stroke does not automatically equate to a shared sense of belonging and understanding as stated by Bourdieu:

> *"[i]f you want to launch a political movement or even an association, you will have a better chance of bringing together people who are in the same sector of social space (for instance, in the northwest region of the diagram, where intellectuals are) than if you want to bring together people situated in regions at the four corners of the diagram"* (1989: 17).

Coming together because of a health condition alone is fundamentally different than coming together because of a political grievance (although there can be political movements anchored on health concerns) or a love of art or a particular sport where durable linkages often reinforce both strong and weak social ties, and are fundamental to the embodiment and objectification of cultural capital through action and practice.

These shared interests speak to the illusio and social libido; they provide meaning and emotional attachment. Stroke can produce a considerably wide and divergent set of impairments and can happen to anyone at any age and from any background, with differing habituses and ultimately different positions within the wider, more general social field. This means that a stroke and acquired impairments could represent a tenuous link as opposed to a durable one. This link becomes ever more tenuous if the reason for coming together, that is stroke and associated bodily and social change, is not explicitly considered or discussed. This ultimately questions whether stroke support groups represent a fallacy if they do not form a genuine, meaningful resource. However, creating durable links and transforming connections into capital within such groups is possible:

> **Frank:** *… there's a man [at the support group] and …his job is arranging things for people …one time he, he, he asked "would anybody like to, to draw or paint" or do any various things. Now I couldn't, drawing and all that … But then they said "does anybody want to sing?" and I said "well yeah okay"…he said "now it doesn't matter whether you can sing, if you just make a noise" … there's a lady who runs the singing … And she's really, really good… We went to see a thing in city square and erm there were all different people come to sing that day and really great ... It's stopped now but will start again at a later date.*

Frank's experience of the aphasia support group was far more positive because the group were encouraged to become involved in activities they might enjoy and thus ignited the *social libido* and enabled a positive emotional experience. These activities gave Frank's attendance at the group a real value and avoided the support group becoming merely a coming together of people whose only commonality was aphasia and stroke. By providing more than a vacuous coming together of stroke survivors, stroke support groups can be of value and an instil a sense of value in those who use them.

6.5.2: Better Dead Than *More* Disabled: Stroke Support Groups, Social Comparisons & Paradoxical Self-Devaluation

As was highlighted within the introduction to this thesis, societal views of disability are often in-keeping with a 'personal tragedy' model of disability, to reiterate:

> *'…better dead than disabled... [t]he erroneous idea that disabled people cannot be happy, or enjoy an adequate quality of life'* (Swain & French, 2000: 473).

This personal tragedy model is also exposed within the concept of the 'disability paradox' which rests on the following question:

> *"…why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external*

observers these individuals seem to live an undesirable daily existence?"

(Albrecht & Devlieger, 1999: 977)

The very process of considering and posing this concept reinforces the view that disabilities and illnesses are assumed to be an all-encompassing and negative experience. In other words it reinforces the personal tragedy model. Part of this problem is that 'healthy' or non-disabled people can focus on the apparent limitations of disability and illness without accounting for either the potential to adapt to impairment or the other aspects of people's lives which are not impacted upon by disability and illness (Ubel *et al.,* 2005; Dunn & Brody, 2008). Thus the impact of disability and illness can be overestimated. Within the current study the personal tragedy model surfaced during discussions regarding both stroke support groups and other stroke survivors.

While those attending stroke support groups could find the groups did not meet their needs and wishes, for others the very notion of a stroke support group was off putting:

Victoria*: … you're better off around fit people*

Greg: *I have no desire to sit with other stroke survivors. I don't want to be reminded of how bad it could have been*.

As individuals who have experienced an able-bodied existence and have become disabled, stroke survivors will have absorbed the attitudes underpinning the personal tragedy model within their habitus. As such despite his / her disabled status the personal tragedy model remains pervasive within their perception of disabled people; better dead than *more* disabled. Negative emotional responses of fear and antipathy are apparent in Greg's wish not to be reminded '*how bad it could have been'*. Therefore, the potential advantages stroke support groups and the support individuals within them could offer, be it informational or emotional, can be less important than avoiding being surrounded by disability. The social capital these groups could provide is thus undermined by their apparent lack of symbolic capital. By avoiding stroke support groups the stroke survivors were avoiding being associated with negative symbolic value and also avoiding the negative *emotions* they evoke. Comments such as these were not limited only to stroke support groups but also made in regard to the stroke survivors more generally:

> **Niall:** *I feel lucky when I look back to the other people in the ward with me, some of them were more handicapped … When I see them I realise how lucky I was*
>
> **Max:** … *it could be a lot worse from what I saw in hospital.*

Again the 'personal tragedy' model of disablement characterises these comments however they also represent a form of downward social comparison. This phenomenon among stroke survivors has been reported elsewhere (Morris & Morris,

2012). For many of the participants this form of social comparison enabled a positive emotional response to their own embodied self, characterised by the emotional response of feeling lucky. However, these social comparisons were not wholly positive acts as they were, and are, fundamentally devaluing of disabled people, fellow stroke survivors and ultimately of the individual who utters them. The stroke survivors expressed views in which those with disabilities were either worthy of pity or too uncomfortable or personally threatening to be around; again better dead than *more* disabled. Such comments suggest a complex and layered form of symbolic violence:

> *'…a body knowledge that entices the dominated to contribute to their own domination by tacitly accepting, outside of any rational decision or decree of the will, the limits assigned to them'* (Bourdieu 1998: 12).

Stroke survivors with impairments are disabled. In delegitimising other stroke survivors with disabilities they are performing symbolic violence upon themselves by association. Downward social comparison can provide a positive sense of self however it also paradoxically devalues the self and reaffirms society's perpetual *othering* of people with disability.

6.6: SUMMARY & IMPLICATIONS FOR PRACTICE

This chapter has presented the findings from a theoretically driven thematic analysis which focused on the impact of stroke on how the individual negotiates their social capital and their sense of place in social space. The role of emotions has been exposed

as a key player in the process of embodiment. Family based social capital, with its layers of interwoven history, enabled the development of an emotional co-dependency held together by affectual obligations and loving dispositions. This deeply embedded and embodied sense of obligation meant that family members typically provided the stroke survivors with core practical and psychological support. However, this sense of obligation also became problematic. The support offered by family members could shift to domination and thus work to restrict the stroke survivor's sense of agency. The weight of emotional support could also lead to the stroke survivor's family members delegitimising the stroke survivor's sense of grief regarding their impairments. Additionally the stroke survivors themselves did not wish to burden their families by requesting further assistance. This resulted in them embodying a sense of guilt which resulted in practices and actions of personal restriction and limitation.

Bourdieu cites sympathy and antipathy as the emotions which underpin social interaction. However, the findings within this study suggest that ambivalence also plays a crucial role. The stroke survivor's sense of their position within socio-spatial fields became endowed with a sense of ambivalence which came to impact upon their action and practice. As such, not only should the role of emotions be given greater credence within Bourdieusian analysis, particularly of social capital and social position, but the role of ambivalence in the process of embodiment perhaps requires further consideration.

Acknowledging disability was a site of tension and created emotions of shame and self-stigmatising attitudes. This sense of shame could also lead to attempts to conceal impairments and disability. This reflects the ubiquitous and insidious nature of ableism within society where disability represents illegitimacy and lack of value within social spaces. This negative attitude towards disability also impacted on the stroke survivor's views of fellow stroke survivors. Such people were deemed to be both pity worthy and a reminder of their own vulnerability. As such fellow stroke survivors were a source of discomfort and fear. Not only do able-bodied individuals fear interactions with disabled bodies (Shakespeare 1994), so do those with acquired impairments exposing that such ableist beliefs remain embodied despite of, and potentially because of, a personal and bodily experience of disability. This potentially exposes the pervasiveness and insidious power of the ableist doxa which is perpetuates within society.

By utilising Bourdieusian thinking the findings presented here have thus shown the usefulness of thinking with Bourdieu in exposing the complex and nuanced role of symbolic violence, for example. However, by utilising empirical data to explore Bourdieusian ideas the findings presented here have also unpicked a deeper level of social interaction beyond what Bourdieu himself offers and has exposed the role of emotions within the negotiation of social capital and sense of place within social space. It should be noted, however, that this more nuanced consideration of social capital has been achieved through a reconsideration of Bourdieu's use of emotions and by bringing into the analysis lesser used concepts such as illusio. Therefore, these findings represent a creative utilisation of Bourdieu's work and Bourdieusian thinking.

6.6.1: Implications for Practice

Despite that fact that stroke can result in severe disability and chronic illness, stroke services remain chiefly concerned with acute care and early community rehabilitation (Sumathipala *et al*., 2010; McKevitt *et al.,* 2011). There are increasing calls for patient centred stroke services designed to address long-term needs (Scottish Government 2009a; McKevitt *et al.,* 2011; *The Stroke Association* 2012, 2013) yet there has been relatively little research into the perceived needs of long-term stroke survivors (Murray *et al.* 2003, McKevitt *et al.* 2004, McKevitt *et al.* 2011). The findings presented here are in-keeping with previous findings which have suggested that long-term stroke survivors can face a number of continual challenges and needs (McKevitt *et al.,* 2004; McKevitt *et al.,* 2011; Sumathipala *et al.,* 2012; *The Stroke Association* 2012, 2013). Therefore, services for long-term stroke survivors should be given greater prominence and considered as fundamental to enabling stroke survivors, and their families, to cope with the challenges they continue to face years after discharge.

Access to Clinical Psychology & Other Services

The findings presented here suggest key challenges faced by long-term stroke survivors are embedded within family interactions and within familial social spaces. While family members offered considerable support to the stroke survivors this support is imbued with nuanced tensions. As evidenced elsewhere acquired impairments and disabilities following stroke can place considerable strain on both the stroke survivors and their family member, and of course, these relationships themselves (Coughlan & Humphrey, 1982; Sjogren, 1982; Teasell *et al.,* 2000; Banks & Pearson, 2004; McPherson *et al.,* 2011; Denno e*t al.,* 2013). The findings presented here also expose that the stroke survivors, despite having lived with their altered bodily status for years, continued to

experience a sense of loss and grief regarding this altered status. While family members could offer support, this support could be limited and potentially delegitimise the stroke survivor's right to their feelings of grief. It has been suggested elsewhere (*The Stroke Association* 2013) that the emotional impact of stroke is considerable and potentially continual. The charitable body, *The Stroke Association* has recommended increased access to clinical psychology services to assist stroke survivors in coping with their emotions. Other studies focusing on traumatic brain injury (which can have similar outcomes to stroke) also promote the importance of psychologically therapeutic programmes designed to aid reconstruction of 'self-narratives' (Nochi, 2000). The findings presented here back such recommendations; not only would access to clinical psychology services aid the stroke survivor, these services could also help to remove some of the emotional burden experienced by the stroke survivor's family members.

A number of studies also suggest that self-management programmes and mindfulness programmes, that are family orientated, can be beneficial to both the stroke survivor and their family (Jones & Riazi, 2011; Fryer *et al.,* 2013; Lawrence & Kinn, 2012, 2013; Lazaridou, Philbrook, & Tzika, 2013). Self-management can be defined as:

> "…*an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent with living with a chronic disease"* (Barlow *et al*., 2002: 178 [cited in Lennon, McKenna & Jones 2013])

Self-management programmes typically aim to modify behaviours and enable individuals to manage their condition by training them in appropriate skills designed to help them monitor their condition and address their social concerns (Lennon, McKenna & Jones, 2013). As Lennon, McKenna and Jones explain:

> *"[s]elf-management programmes are distinct from patient education or skills training in that they are designed to enable people to take an active part in managing their own condition, including the psychosocial consequences and lifestyle adjustments required to enhance quality of life"* (2013: 868)

Due to this onus on providing the individual with the stills to both manage their health and the psychosocial consequences of living with chronic disease (and in the case of stroke this can be extended to disabilities) such programmes could be beneficial to long-term community dwelling stroke survivors. Mindfulness, as Cassidy *et al.* explain, involves:

> *"… moment-to-moment attention and observation of external and internal stimuli (eg. thoughts, feelings, bodily sensations) in a non-judgemental and non-reactive way"* (2012: 644).

Mindfulness training can involve developing skills for '*mindful meditation practice, mindful awareness during yoga postures, and mindfulness during stressful situations and social interactions*' (Grossman, 2004: 36). There is some evidence to suggest that mindfulness training can reduce stress and anxiety within patient groups with chronic conditions, including stroke (Grossman, 2004; Cassidy *et al*., 2013; Lawrence *et al.,* 2013). As emotions played a considerable role in the embodiment process for the stroke survivors within this study, mindfulness training could prove helpful in enabling the stroke survivors to manage their thoughts and feelings.

However, research into both self-management and mindfulness training for stroke survivors are in their infancy and current research is focused on the rehabilitation phase of stroke recovery with few such interventions directed towards long term stroke survivors (Lennon, McKenna & Jones, 2013; Lawrence *et al.,* 2013). However, what evidence there is does suggest such training can be beneficial for chronic conditions (Lennon, McKenna & Jones, 2013; Lawrence *et al.,* 2013). As the stroke survivors within this study, and others, continue to face on-going challenges in light of their impairments such programmes should be made available to long-term community dwelling stroke survivors in order to aid their continual recovery.

Creative Approaches to Stroke Support Groups

An alternative form of social support for stroke survivors are stroke support groups. There is some evidence to suggest that peer support groups can have positive impacts for stroke survivors (Amarshi, Artero & Reid, 2006; Weltermann *et al.,* 2000; Roman, 2008). However, the findings of this study suggest that such groups can be viewed as

negative and the stroke survivors who attend such groups pitied and feared. This is particularly problematic as it reveals that stroke survivors view those they believe are 'worse off' in a negative light which perpetuates negative societal stereotypes of disabled people. Charitable organisations can reinforce negative stereotypes of the '*charity cripple'* (Davis & Watson, 2002) and as such more inventive and non-ableist representations of those with stroke and other impairments would be required in order to counteract such negative views. Issues of fear regarding other stroke survivors could also be tackled by discussing fears and concerns with fellow stroke patients during the rehabilitation phase or via clinical psychology which could also assist in reducing such fears.

The findings presented above also expose that stroke support groups could fail to meet expectations. In order to improve the potential benefits gained from stroke support groups, awareness of individual needs and structured support is required. However, as many stroke support groups are run by community volunteers this could be difficult to implement. A nationwide network for those running stroke support groups could offer the opportunity for the sharing of ideas and could also improve both awareness of support groups and the structure such groups take in the future. This would require considerable organisation, funding and imaginative approaches to raising awareness and encouraging engagement. However, as discussed above a key problem with stroke support groups may be that getting together purely due to a health condition simply holds little interest; it does not inspire the social libido. Ultimately, long-term community dwelling stroke survivors should be provided with varied options to assist them with their on-going recovery.

Increased Awareness & Training for Employers

The world of work presented a number of challenges for stroke survivors with impairments. The struggles they faced within these socio-spatial fields created fears, anxiety and a sense of shame. Many of the challenges faced where the result of the environment, attitudes of employers and the individual's own emotional response. These findings suggest that employers require greater guidance and training in order to accommodate those with impairments within the work place, for example, the creation of quiet spaces to work and raising awareness among staff regarding the needs of individuals with physical and cognitive impairments (Gilworth *et al*., 2009; Edwards & Imrie, 2003; Alaszewski *et al*., 2007; *Different Strokes,* 2002). The stroke survivor's emotional requirements again could be tackled with access to clinical psychology or other talk-based therapies.

Finally

Simmering the emotions experienced by stroke survivors as they negotiated their social capital and manoeuvred within socio-spatial field threatens to produce a (de)valued identity problematised by becoming disabled in a society where disabled bodies are still viewed as illegitimate, and by the sense of loss and grief created by impairments themselves. The following chapter considers the development of a devalued identity in greater depth and also presents an adaptation of the concept of dispositions; 'phantom dispositions'. This concept highlights the manner in which the body and habitus can become out of sync and the role social fields can play within this process.

CHAPTER 7: PHANTOM DISPOSITIONS & DEVALUED IDENTITIES

7.1: INTRODUCTION

The core objective of this thesis was to explore the long-term experiences and perceptions of stroke survivors living within the community. An essential part of this exploration was the use of Bourdieusian thinking to inform both data collection and analysis inviting the opportunity to explore, expand and potentially adapt Bourdieusian concepts. The first few chapters of this thesis provided an overview of stroke as a chronic illness and a cause of disability, Bourdieu's thinking tools and the methodological approach used. Chapter 6 made a case for giving greater credence to the role of emotions in acquiring and maintaining social capital as a stroke survivor, and the difficulties impairments can present for manoeuvring within socio-spatial fields.

The concern of this chapter is to consider key interrelated themes which emerged from the theoretically driven thematic analysis. In order to do this an instrumental multiple case study was utilised. The first of these themes is a theoretical adaptation of the concept of dispositions, 'phantom dispositions'. This adaptation was born out of the apparent disconnection between historical dispositions and practice due to acquired impairments. Certain dispositions, while still informing the individual's habitus can no longer be realised in practice much like a phantom limb is subjectively felt yet externally non-existent. The second of these themes is 'devalued identity'. This theme was touched upon in the previous chapter. It is concerned with bodies as bearers of value and the disabled body bearing considerable (negative) symbolic weight. It encapsulates the embodiment of the negativities associated with disability

and a resulting dissatisfaction with the illusio on one hand and a shift in the site of conatus on the other. Ultimately the habitus becomes somewhat '*divided against itself*' (Bourdieu, 1999: 4) and out of sync with the body. This results in the habitus becoming moored between two worlds of the able bodied (valued), where historic dispositions were formed, and the disabled (devalued), where new dispositions are required and others are phantomised. The habitus thus becomes lodged in a liminal state. The following sections have been split by these themes respectively. In order to present these findings there will be some reiteration of issues highlighted within pervious chapters.

7.2: PHANTOM DISPOSITIONS

> *"Many patients awake from the aesthetic after an amputation feeling certain that the operation has not been performed. They feel the lost limb so vividly and clearly that only when they reach out to touch it do they realise it has been cut off. This startling realisation does nothing to subdue the reality of the limb they experience and may even intensify the sensations that define it"* (Katz 2000: 45).

As the excerpt above illustrates amputees can experience the phenomena of phantom limb following their amputation. After Lord Nelson lost part of his right arm during The Battle of Santa Cruz de Tenerife in 1797, he is said to have experienced the sensation of fingers pressing into his missing palm, which he believed provided direct evidence for the existence of a soul; if a mere fragment of the body can exist beyond its physical being so can an individual person (Ramachandran & Hirstein, 1998). Phantom limbs

can present ghostly sensations of the lost limb. The individual feels as though the limb is still part of them, still connected with them, they can even feel pain within the phantom, yet while the limb is still subjectively felt it has no existence in reality and therefore cannot function in reality. The limb, both before and after the amputation, will have formed part of that individual's history. The knowledge of having had the limb, how to use the limb and ultimately what it *meant* to have the limb remains despite the individual's inability to use it in reality.

Within this section of this chapter the phenomena of the phantom limb will be used as a metaphor to discuss the experience of *phantom dispositions* within the bodies of stroke survivors. As such the purpose of this section of the chapter is to present an argument for this theoretical adaptation of Bourdieu's concept of dispositions. The first step in the presentation of this argument is to provide contextualisation and therefore the case used to explore this theme, Catlin, will be given a brief summary before the argument for phantom dispositions is put forward.

7.2.1: Caitlin

Catlin was employed full-time prior to her stroke and was married three with children. She lived within a busy, large urban area off a main road. She was of Asian descent as was her husband. The interview took place within the large living room of her cottage with an ever present hum of traffic passing outside and the occasional distraction of her husband moving through the cottage as he got ready for work.

Catlin had experienced three strokes however the first two were not diagnosed until the event of the third, as she explained:

> *I had one first and went into hospital. I woke up and fell on the floor… I was in for five weeks but they couldn't find anything … I wasn't well after that, you just know you're body isn't well, just ill. I think even the doctor got fed up of me "there's nothing wrong with you, you haven't had a stroke or anything"… then I was admitted with a stroke and it was at that time that they realised I'd had another. I'd had three in total but this time it was quite bad.*

While in hospital Catlin had experienced aphasia which had since dissipated with only the occasional occurrence of word retrieval problems. Catlin's third stroke did, however, leave her with memory and learning difficulties and fatigue which she struggled to manage, particularly within the work environment. Catlin had returned to work following her stroke in a new role. These impairments caused her frustration;

> *I was quite clever before my stroke … I get a bit annoyed with myself. I think "I could do that before, why can't I do it now"?*

The lack of explicit physical evidence of her stroke was problematic for her in relation to both her relationships with colleagues and family members;

> *...it's just really difficult because you're so normal on the outside; it's hard to explain to people how you feel on the inside.*

Much of Catlin's interview was pitted with concerns regarding maintaining a façade of 'normality'. This entered into her views on family and her cultural background:

> *…because of the Asian people, like I say it's really hard in our culture. Even if you've got an illness you try and cover it and try and be normal*.

Being able to maintain this façade became particularly problematic for Catlin within the work environment where noise and apparently unaccommodating behaviour from work colleagues made balancing the demands of her job with her impairments problematic. However, the relationships she made with fellow patients during her time in rehabilitation provided an escape from maintaining a façade:

> *I think it is because I can just be me with them, I don't need to be somebody else because they know 'coz they've had it as well.*

The key theme within Caitlin's interview was a disconnection from her historically learnt dispositions, compounded by her belief that those around her expected her to be 'normal': to be her pre-stroke self. Caitlin was not only disconnected from her dispositions by her impairments but also by the environments she manoeuvred within and the demands others placed on her. Due to this Catlin provided an ideal candidate to explore the process through which an individual's dispositions can become phantoms, or phantomised, by both impairments and external environments (fields)[15].

[15] Note: The emerging theme of 'phantom dispositions' appeared within 11 other interviews typically occurring in interviews in which the interviewee's impairments resulted in them being unable to fully engage with activities of value to them such as hobbies, interests and work. When this theme appeared within the interviewee's accounts were typically peppered with a sense of frustration or loss and were bound up within struggles to reconcile the pre-stroke self with the post-stroke self.

In the following sections the key Bourdieusian thinking tools of dispositions, habitus, bodily hexis and capital, particularly cultural and physical capital, are **revisited** in relation to Caitlin's account of her experience of her impairments in order to present a case for phantom dispositions.

7.2.2: The Role of Bodily Impairments in Phantomising of Dispositions

Habitus is often privileged above dispositions within Bourdieusian analysis which is typified in the many types of habitus discussed within the literature, for example Parkin and Coombers' (2010) '*public injecting habitus'*, Rimmer's (2010a and 2010b) '*musical habitus'*, and Gould's (2009) '*emotional habitus'*. As argued within Chapter 2 these 'habitus types' are problematic and potentially reductionist. Habitus is an incredibly useful concept, however, attempting to categorise individuals and groups by the notion of them holding a type of habitus may be a shallow use of a complex idea which is enmeshed within a wider method of thinking; the Bourdieusian toolkit. It was argued in Chapter 2 that perhaps Bourdieusian scholars, and others who call upon Bourdieu's concepts within their analysis, could take a step back and consider the importance of what makes up the habitus: dispositions. This argument is furthered here. Embodied dispositions are both generative and transposable; '*they are capable of generating a multiplicity of practices and perceptions in fields other than those in which they were originally generated'* (Bourdieu, 1991: 13). It is dispositions which enable creativity and spontaneity in action and practice and therefore a change in dispositions, or the acquiring of new dispositions, rests at the heart of change in the habitus.

Dispositions are revealed in the notion of bodily hexis, the socially inscribed manner in which individuals '*carry themselves*' (Bourdieu 1984: 218). Habitus, the container of dispositions, is, therefore, not merely a state of mind but also '*a bodily state of being*' (Wainwright & Turner, 2006: 241). Dispositions, habitus and bodily hexis are founded in the semi-conscious nature of practice and habit, rather than in fully consciously learned rules and principles; a practical logic based on the logic of practice. What is most important for an individual habitus is its historicity[16]. Habitus contains the past, present and (possible / probable) future; it is historical and present as well as the co-creator[17] of future history. Bodily dispositions not only inform semi-conscious action and practice but are a series of interwoven pieces of individual history collected as the individual body has moved in, through and between spaces and encountered the other individual bodies that occupied those spaces. These historical bodily dispositions are also, in the day to day lives of individuals, durable:

> *"[d]ispositions are long-lasting: they tend to perpetuate, to reproduce themselves, but they are not eternal . . . Any dimension of habitus is very difficult to change but it may be changed through the process of awareness and of pedagogic effort"* (Bourdieu, 2002: 29).

In the case of stroke survivors, or indeed others with acquired impairments, the learned dispositions of the habitus are not changed due to a purposeful wish to re-educate the body. Rather, their bodily dispositions become threatened and altered by

[16] In the philosophical sense of having a historical origin and developing over time
[17] Working in relation to field

a sudden and catastrophic transformation within the body itself. This represents a considerable challenge to the apparent stability of dispositions as Edwards and Imrie muse:

> *"[f]or someone who suddenly becomes disabled, the learned dispositions of the habitus may be ruptured. Practices may have to be learned, or unlearned in a conscious, thoughtful way. For disabled people, practices that are usually spontaneous may not be so thoughtless"* (2003: 243).

The rupturing of dispositions is a fitting description for the impact of acquired disabilities and impairments and reveals how vital the body is in the production and utilisation of dispositions. The body is ultimately the conduit through which the individual and the world they occupy become interwoven and a disruption in this conduit ruptures this relationship. Dispositions, in a sense, *may* only be as durable as the body they exist within. As Edwards and Imrie suggest despite the potential for a disability to rupture the habitus it is possible for dispositions to be consciously relearned or unlearned depending on the context and nature of the disability. However, what happens to those dispositions, mental and physical skills which cannot be fully relearned no matter the pedagogic effort? These dispositions will have been, for the most part, taken for granted in the day to day lives of the individual prior to disablement. The sudden loss of dispositions problematises the bodily hexis making these dispositions fully conscious due to their absence and the memory of their existence; these dispositions remain within the individual history of the habitus and

the body yet cannot be actualised in practice. With the presence of impairments the body ultimately denies the habitus the opportunity to objectify itself through the body because these dispositions are there but not there. They are phantasms both embodied and disembodied. This ultimately leads to a frustration at the self, encapsulated by Caitlin's comment:

> *"I'll still be trying to do things and I'll get really angry because I can't do them. I'll forget or I'll leave things on the cooker - I love cooking but I'll leave things on the cooker and I'll just think 'this isn't me' …that's when I get a bit annoyed with myself. I think "I could do that before, why can't I do it now"'?*
>
> **[Later]**
>
> *"Or somebody will ask me something … and I'll get a total blank and I'll think 'what did they say' and I'll have to go back and sit at my desk and think and it'll come back to me eventually … stupid things – well not stupid things but things like that really affect me now... I do find it difficult sometimes because I've found that if somebody tells me something I need to be told two or three times whereas before I'd of picked it up straight away…"*

Such comments were interspersed throughout Caitlin's interview. Caitlin knew that the event of her third stroke had caused her cognitive impairments however this knowledge did not enable her to reconcile what she could do prior to her stroke with

her post-stroke capabilities. This reflects the taken for granted and engrained nature of the habitus in the body:

> *"…habitus not only operates on the level of everyday knowledgeability, but is inscribed onto the body, being revealed in body size, volume, shape, posture, way of walking, sitting, ways of eating, drinking, amount of social space and time an individual feels the right to claim, degree of esteem for the body, pitch, tone of voice, accent, complexity of speech patterns, body gestures, facial expression,* ***sense of ease with one's body****…"* (Featherstone, 1987: 64 [emphasis added])

The sudden disconnection from, and thus phantomising of, dispositions creates a rupture in both the habitus and the bodily hexis and thus the 'sense of ease with one's body' is lost. Due to the historical nature of both habitus and bodily hexis, the individual's sense of self, and sense of self in socio-spatial fields becomes problematic. This is because the memory of habits, abilities and skills (dispositions) remains; those aspects of identity, inscribed within the body, are still part of the habitus in a historical sense yet no longer realised in practice. Due to the taken for granted nature of dispositions, and thus the unconsciousness of day to day practice and action, a sudden disconnection between dispositions and the body is not necessarily a loss that can be overcome and easily adapted to. The individual's corporeal identity thus becomes a site of frustration and confusion in the same manner as that of the phantom limb.

With the habitus and bodily hexis out of sync, the body and its place within socio-spatial fields is no longer a manner of semi-conscious habitual action, in fact the reverse occurs. The body and its lost capabilities becomes a site of vulnerability and anxiety because it is no longer endowed with the innate trust that it once was:

Caitlin: *I'm still not very confident. I get quite down sometimes because [eyes begin to well up] I just don't have the confidence whereas before… I know I should go out more but I look outside and I say no…*

Interviewer: *Is that since your stroke?*

Caitlin*: Oh yeah, so many things since my stroke. I just find it really hard sometimes especially if it's really crowded. I was in [the supermarket] the other day and it was really busy… I just had to drop everything and come back out… I used to be really confident before but now [pause] I used to always stick up for people you know but now I back away because I'm scared or haven't got the confidence, I'm really aware of not wanting to upset people, I'm wary of facing up to people [in an argument] now… and all the normal everyday things at work I find really hard, I have to write everything down and I have to have a routine whereas before I just knew what I was doing whereas now I've got to sit and think. I had to get a satnav because I can't I can't remember the street names. I get very frustrated.*

Much that was taken for granted becomes fully considered. Bodily re-orientation and alternative responses to manoeuvring within social space are necessary as exposed by Caitlin's changes in her behaviour: avoiding confrontation, writing everything down, using a satnav. New dispositions are developed in order to manoeuver within socio-spatial fields with impairments, yet this requires conscious pedagogic effort. While Caitlin is re-educating her body, the frustration she encounters in spite of her efforts to accommodate her impairments bears the hallmark of phantom dispositions. To reiterate the comments made at the beginning of this section, when an individual loses a limb to accident and amputation and goes on to experience the phantom presence of the lost limb, that individual feels as though the limb is still part of them, it's presence is still instinctively sensed yet it has no existence in reality and therefore cannot function in reality. This limb will have played a key role in the development of that individual's history; awareness and deep embodied knowledge of what it was like to have that limb, how instinctively the limb was used in day to day activity remains within that individual's habitus making the loss of the limb acutely felt and apparent. Losing the ability to carry out everyday tasks without impairments is just as acutely felt precisely because the ingrained experience of negotiating the world through semi-conscious, taken for granted practices remain in the history of the now impaired individual.

The concept of 'phantom dispositions' speaks to other theories of identity disruption, such as 'biographical disruption', 'biographical work' and 'identity reconstitution' (Bury, 1982; Bury, 1991; Charmaz, 1983; Corbin & Strauss, 1987). Such theories highlight how illness can impact upon an individual's identity, or sense of their

biography, and illness is viewed as something which jeopardises an individual's sense of the taken-for-granted world. Such disruption requires a renegotiation of identity, relationships, and ultimately a changed conceptualisation of the future. However, while such theories of disruption provide a framework for understanding the alterations between the self and the social, the role of the body often becomes lost within the narrative of such theories. The concept of 'phantom dispositions' offers the opportunity to theorise and explore not only changes in identity, selfhood and sense of self within social space but also offers the chance to explore the potential disconnect between the self and the *body* itself through the lens of both embodiment and disembodiment. Furthermore, this concept brings the historicity within the body to the fore; the frustrations and associated difficulties in sense of self which occur due to the loss of ability is not just a matter of loss but of *memory*. Crucially in the case of Caitlin, and other individuals with acquired impairments, the adjustment period between being able-bodied to disabled can be considerable and perhaps continual; the impairments can never be entirely ignored, always present and never past and always tinged with the enduring memory of able-bodiedness.

However, dispositions, habitus and bodily hexis do not operate in isolation but in relation to socio-spatial fields. As will be explained below the demands, expectations and norms of a field can also phantomise dispositions.

7.2.3: The Role of Fields in Phantomising Dispositions

According to Bourdieu and Wacquant:

> *"… a field consists of a set of objective, historical relations between positions anchored in certain forms of power (or capital)"* (1992: 16).

As such '*a capital does not exist and function except in relation to a field*' (Bourdieu & Wacquant, 1992: 101) and furthermore bodily dispositions, are not governed solely by the habitus, but by their affiliation with social fields. Individual bodies and the individual's bodily hexis are shaped in '*accordance with the fields in which they are involved and the demands of those specific fields'* (Crossley, 2001: 107). The value of the individual body and the ability of that body to manoeuvre itself successfully depend upon the field(s) it occupies. It can be argued that bodily *value* ultimately depends on the physical and cultural capital demanded by that field and whether the individual's bodily hexis satisfies this demand. However, both of these forms of capital are particularly vulnerable. Both incorporated (embodied) cultural capital, which is of course embodied as dispositions, and an individual's stock of physical capital are ephemeral: they live, decline and die with their bearer (Shilling, 2003; Wainwright & Turner, 2006).

The decline of one form of capital can shift the weight of value onto another as exemplified in Wainwright and Tuners' (2006) examination of the deterioration of the bodies of ballet dancers. The authors have argued that the habitus of ballet dancers can become '*fractured*' (2006: 241) by injury or advancing age and this loss of bodily competence can result in diminished physical capital. This threatens the ballet dancer's

value and legitimacy within the field. Yet, for ex-ballet dancers the culture of ballet is so ingrained that it is possible to offset the deterioration in physical capital and associated bodily dispositions by utilising their abundance of cultural capital, that is, their incorporated knowledge of ballet, in order to teach ballet. While their declining physical capital may mean that the ballet dancers can no longer use their bodies *explicitly* within this field, the embodiment of the culture of ballet within the habitus means they can teach, thus converting their physical capital into cultural capital (and economic capital). Their bodies ultimately remain enmeshed within the cultural field of ballet. The incorporated cultural capital, which as Robbins asserts is '*indistinguishable from habitus*' (2000: 34), means that the bodily dispositions which provided physical capital are still accessible by proxy as opposed to becoming fully *phantomised* due to the highly specific nature of the field of ballet.

Habitus is culture in the body; it is our class, but also our skills, our interests and our values therefore Wainwright and Turners' ballet dancers can shift from one position to another with relative ease. For Caitlin, however, this was not the case. In order to return to work Caitlin had been given a new role which she was not fully accustomed to:

> *'I mean the job I had before … I feel I probably could have done that now [better] than what I'm doing now because [the new job is] more complicated and it's a lot of figures … I'm the only person within the [department] to have come back to work after a stroke and I was offered this post. I probably would have been able to do it before I had the stroke*

> *but I find I struggle … I'd had previous job experiences so I thought I'd manage but I didn't realise it would be so complicated to do the job …*

Her historical dispositions were, in part, shaped by her employment history. She had acquired, prior to her stroke, dispositions which enabled her to successfully negotiate the field of work; a '*practical mastery*' (Robbins 1991: 1) of her situation developed through numerous historical encounters. This is because habitus, in Bourdieu's words:

> *"…ensures the active presence of past experiences, which, deposited in each organism in the form of schemes and perception, thought and action, tend to guarantee the "correctness" of practices and their constancy over time"* (1990b: 54).

However, unlike the field occupied by ballet dancers, Caitlin's transition from one position to another was not a case of utilising one form of capital, or set of dispositions to offset the loss of another. Some of the historical dispositions which could have been called upon to in order to fulfil the new role were phantomised by her impairments. Compounding this, her ability to develop new dispositions and thus adapt to her new role were also problematised due to the nature of her impairments; memory and learning difficulties and fatigue. As such Caitlin's ability to enact her embodied cultural capital within the field of work, or acquire and maintain cultural capital, was compromised and an alternative was not available. However, impairments alone were

not the sole cause of this, the nature of the field also posed a problem. As Maton states the:

> "*…relationship between the structure of a field and the habituses of its members [is] one of varying degrees of fit or mismatch*" (2010: 57).

This relationship between habitus and field has a direct impact upon the actions of individuals. What appears to have occurred in Caitlin's scenario is a change in the *degree* of fit and mismatch. She remains able to manoeuvre within this field but without the relative ease or taken for granted ease she once did. Caitlin is still 'a fish in water' but she can no longer take the water around her for granted because it has become difficult to swim:

> *They [people at work] don't exactly understand… I think sometimes it's the comments people make… It's like they'll say things like "are you stressed" you know? It's a question they're asking me but it's more like an answer; "you're really stressed aren't you?" and I'm like "no". It's things like that and it's like, "if you just sit and listen to me and let me explain" but they don't let me explain what I'm trying to say … I find that quite frustrating …*
>
> **[Later]**
>
> *I don't want to be treated differently but … you're straight into the work and it's quite noisy. I don't pick up it all now - my brain doesn't [pause]. If*

> *my manager comes to say [something] to me and it's noisy or people are having a laugh [talking jovially and loudly] it doesn't filter through the same as it would before and then I'm like "sorry what were you saying" and my brain gets all muddled up and sometimes I have to go up to her and say "sorry I didn't quite pick up what you said" [but] she knows, she knows I'm not as quick as I was…*

The above excerpt exposes the forces of fission and fusion between embodied dispositions and field. It is not merely impairments which make it difficult (or impossible) for historical bodily dispositions to be realised or actualised but the nature of the field. Caitlin states that her employers do not appear to understand, they assume she is 'stressed' and, according to Caitlin, will not allow her to explain why she sometimes struggles. The attitudes, or dispositions, of those within this field appear to be unsympathetic to or misunderstand Caitlin's situation. Compounding this is the physical environment of noise which worsens Caitlin's ability to understand what is being asked of her. As Sayer states *'[i]t is not thanks to our knowledge that walking on water doesn't work, but rather the nature of water'* (1992: 70 [cited in Wainwright & Turner 2006: 245]). Therefore, while impairments within the body can create a disconnection from historical dispositions, which live on as phantoms within the habitus, the nature of a field can also create such a disconnection. In the latter case the disconnection is not a true phantom, rather a glitch caused by the demands of a field; *sometimes I have to go up to her and say "sorry I didn't quite pick up what you said" [but] she knows, she knows I'm not as quick as I was…*

The potential for the demands of a field to produce a disconnection from dispositions also reveals a more insidious problem. Caitlin's comments on her co-workers' assumption that she is 'stressed' as opposed to struggling to carry out her role due to the noisy environment and her boss' apparent lack of accommodating behaviour, highlights an underlying lack of acceptance and accommodation of her impairments. Social fields, such as that of employment, can (re)produce social and physical structures which highlight and expose the presence of impairment. This was particularly problematic for Caitlin as her impairments were not explicit physical impairments:

> *…it's just really difficult because you're so normal on the outside erm it's hard to explain to people how you feel on the inside… from the outside "oh there's nothing wrong with her, she looks fine". At work it's really hard because you try to do the job and because people don't know what a stroke is, because there are so many different types of it* – ***they keep trying to treat me like a normal person and I keep saying "I'm not normal, I've got an illness"…*** *I don't know if they don't understand it's probably just as I said lack of knowledge*

Caitlin often had to affirm and reaffirm the presence of her impairments to her work colleagues. Impairments and disabilities which are not explicitly observable to others can present problems such as issues with social recognition, deciding whether to declare the presence of disability, and difficulties in being accepted by others as

genuinely disabled (Davis, 2005; Caldwell, 2010; Kooistra, 2008; Samuels, 2003; Valeras, 2010). Being faced with suspicion or lack of recognition creates additional problems on top of impairments as it further problematises the individual's sense of place within the socio-spatial field. In Caitlin's case she was the first individual within her department to return to work following a stroke. She accepted that her colleagues perhaps did not understand, and this lack of understanding caused her impairments to go unaccommodated, resulting in her struggling to fulfil her role. Yet conversely, despite this need to continually disclose her impairments Caitlin also felt the need to put on a façade of able-bodiedness:

> *You try to put this face on you know? Try to pretend everything's okay but you know yourself that it's not. I find that quite hard. Sometimes my manager will come up and speak to me and she'll "rr-rr-rr" rattle on and I'll be thinking "what did you say"? Because it doesn't sink in and I'm afraid to go and ask her again because she might think I'm stupid.*

As discussed within the previous chapter, the presence of disabled people within the work place disrupts '*accepted notions of embodied employment*' (Hall, 1999: 146 [cited in Edwards & Imrie 2003]) because people with disabilities are '*different, expensive, inconvenient, or odd*' (Shakespeare, 1994: 298). Essentially, the world of work operates under a neoliberal, ableist system in which disabled bodies are viewed as less capable and problematic (Wilton & Schuer, 2006; Kumar, Sonpal & Hiranandani, 2012; Edwards & Imrie, 2003). Caitlin ultimately became profoundly aware of the apparent inconvenience her impairments presented. She was made to find work stressful and a

cause of anxiety. Yet more than this, her response of embarrassment - a fear of being thought of as stupid - ultimately exposed an embodiment of her dominated position within the work place.

Therefore, the nature of a socio-spatial field can be considerably problematic in producing an environment which prevents disabled bodies from fulfilling their capabilities and at the same time shames them into accepting the status of an inconvenience. Here an individual's dispositions become further phantomised; not only does the field limit the individual's ability to objectify their habitus through their body due to unaccommodating environments, the nature of that field further limits the individual's capabilities further as that individual comes to embody a sense of shame, fear and anxiety. As mentioned above, unlike the true phantoms of impairments themselves - which represent a disconnection between the dispositions of the habitus and the bodily hexis and are thus located directly within the body - the phantomising of dispositions caused by the nature of a field are fixable and preventable if impairments are accommodated. Within the field of work, for example, impairments can be accommodated by patience shown by colleagues, quiet spaces to work, accessible and clear guidance but also crucially training of employees regarding the nature and thus needs of those with both physical and cognitive impairments (Gilworth *et al.,* 2009; Edwards & Imrie, 2003; Alaszewski *et al.,* 2007; *Different Strokes,* 2002).

This sense of embodied shame and anxiety is linked directly to the second theme this chapter aims to explore; devalued identities. A key aim underpinning the development

of Bourdieu's theoretical toolkit was to provide a means for exploring, uncovering and exposing socio-cultural processes which fortify the reproduction of social inequalities. For Bourdieu the body sits at the heart of this reproduction. As Shilling states within Bourdieu's approach the body is *'an unfinished entity which develops in conjunction with various social forces and is integral to the maintenance of social inequalities'* (1993: 127). Bodies are highly visual and thus loaded with symbolic meanings and values. Becoming disabled can create a negative shift in the value attributed to the body within varying social fields. This shift in value can become embodied within the individual as a deep sense of worthlessness, that is, a devalued identity.

7.3: DEVALUED IDENTITY

7.3.1: Disabled Bodies, Legitimacy & Value

As outlined in the introduction to this thesis the disabled body comes with weighty societal baggage and can be characterised by the 'personal tragedy model'. People with disabilities are often characterised by their perceived 'otherness' and even, to evoke Mary Douglas, as '*matter out of place'*: disabled bodies represent an affront to the civilised and controlled management of the body, encapsulated within Elias' *The Civilizing Process* (2000 [1939]), which remains ubiquitous within modern Western cultures (Hughes, 2002). Those living with disabilities, be them cognitive or physical, historically face inhabiting a body that is largely viewed through the lens of the biomedical model, a model which reduces that identity to '*corporeal deviance'* (Garland-Thomson, 1997: 6). Also outlined in the introduction was the social model which argues that disability is imposed on top of physical or cognitive impairments by

external social oppression. However this model has faced criticism for not effectively accounting for the corporeal (Shilling, 2003) as Wendell asserts:

> *"[i]n most postmodern cultural theorizing about the body, there is no recognition of - and as far as I can see, no room for recognizing - the hard physical realities that are faced by people with disabilities"* (1996: 45).

As discussed within the previous chapter the sense of loss and feelings of grief concerning lost abilities and altered bodies is a real and legitimate experience for stroke survivors. The experiences of those with acquired impairments are not born from either the bodily impairment or social oppression alone: neither the biomedical nor social models of disability quite capture the lived experience of disability. In order to understand this experience the '*socially shaped embodied subject'* (Shilling 2004: 474) must be accounted for.

According to Bourdieu `*the body is in the social world but the social world is also in the body*' (1990: 190). Bodies are (re)produced socially developing a bodily hexis. As discussed above bodily hexis can be viewed as the objectification of habitus and thus exposes the semi-conscious nature of practice and habit, as opposed to consciously learned rules and tenets. That is not to say that individuals do not purposefully learn or train their minds and bodies, however, much of the dispositions that become embodied within individuals become so subtly and over time through social experiences. Bodies are also bearers of physical capital. The production of physical

capital involves the education of bodies in ways which are perceived to be of value within particular social fields:

> *"…practices are incorporated within the body, only then to be regenerated through the embodied work and competence of the body*" (Crossley, 2001: 106).

Physical capital can then be used to acquire or be converted into economic capital, cultural capital, and social capital (Shilling, 2004). The purpose of this section of the chapter is to explore the ways in which disabled bodies can become devalued, developing the embodiment of a devalued identity. The case utilised to contextualise this discussion is Chris, whose interview was loaded with this theme. His personal experience of shifting from a socially dominant, and thus legitimate and valued position of ablebodiedness, into the realm of the dominated, illegitimate and devalued is explored.

7.3.2: Chris

Prior to his stroke Chris, a white British man, was working in a well-paid full-time job, married to his second wife with two children from his first marriage and four step children. He and his wife owned their home in a small, rural town. Chris was interviewed within the University.

His 'stroke story' began, not with a stroke, but with a heart attack; '*there were warnings, I was drinking too much and smoking. My fitness had dropped dramatically… three weeks later [after the heart attack] I woke up and everything was sort of grey and I told my wife I didn't feel right and went back to bed. I'd had a stroke*'. Chris' stroke did not leave him with any physical impairments but it did result in aphasia; '*people think I can speak normally, I can't. I have to rehearse everything I say*'. At the time of Chris' interview he was 65 years of age and 12 years had passed since his stroke. He and his wife lived together and the children were now adults living out with the family home.

During the 12 preceding years Chris' aphasia had improved. However, when in stressful situations or noisy environments the effect of Chris' aphasia would worsen; '*any background noise, air conditioning, traffic on the street… to this day I cannot go to noisy places, you know pubs and things.*' His aphasia made employment problematic with both the stress of interview situations and the noisy environments within workplaces exacerbating his aphasia. At the time of the interview he was attempting to set up his own business due to his difficulty securing and maintaining employment through other means. While his wife still worked the financial implications of Chris' change in employment had presented difficulties; '*my income dropped to a third so there's lots of things other people can do that we can't'.* The loss of his job, loss of the status he attributed to his former role as '*breadwinner*' and the associated reduction in income was something which Chris referred to often throughout his interview. He did not have any long breaks in employment prior to his stroke and he stated within the

interview that he '*never had spare time'* due to the number of hours he used to work. Prior to his stroke working had been a large part of his life and identity.

The lack of physical impairments, the wish to improve his fitness due to both the heart attack and stroke and the spare time obtained due to joblessness had resulted in him joining the gym and becoming involved in sports; '*so the physical side, my ambitions have gone into that – I'm champion for cycling for people in my age group – things like that'.* Despite the success he had found within athletic pursuits he viewed his mental capacities as a '*disaster*'. The spare time also allowed him to engage more in his hobby of stamp collecting; '*that is very important because it gets me away, in a world of my own'*.

His aphasia also impacted on his family relationships and wider social relationships. According to Chris his relationship with his wife had been '*damaged*' by his stroke and resulting aphasia. This was due to his wife's apparent lack of understanding, the difficulties he faced when in noisy environments and travelling which reduced their ability to socialise within public spaces as well as the reduction in income which further restricted their social life. He would struggle to keep up with group conversations, felt he could not reciprocate in friendships and would often choose not to socialise and '*hide away from people*' as a result.

The overriding theme within Chris' interview was one of embodying a devalued identity a theme which will be explored below. This exploration is presented in three

sections. The first of these sections considers processes whereby the disabled body is excluded from access and participation due to the nature of certain social fields. The second discusses the loss of able-bodied *homophily* between the now disabled stroke survivor and the still able-bodied significant other. This enforced *heterophily* brings with it a breakdown the innate ability to understand and interact with one and another which will have been developed over time over countless exchanges. The third explores the process whereby the individual can find a new site for meaning and self-perpetuation, that is, a change in the site of conatus and rekindling of the illusio. This final section highlights the potential of, but also fragility of, attempts to find meaning and joy in existence under the weight of a devalued identity.

7.3.3: Exclusion &the Loss of Status and Distinction

According to Chris Shilling;

> "*… there is an interrelationship between the development of the body and people's social location… the management of the body [is] central to the acquisition of status and distinction"* (2003: 111).

It is this entangled relationship which is at the heart of embodiment and also exposes the symbolic value placed on the body. As the accumulation of physical capital plays a pivotal role in the development of the body and its social position, diminishment of physical capital due to acquired impairment represents a fundamental threat to an

individual's ability to maintain their social position, status and distinction. It is the combination of capital and field which create value and legitimacy as Skeggs explains;

> *"[s]ocial space is the metaphorical means by which the different forms of capital to which one has access … come to have value and legitimacy. So when one enters a physical space such as a bar, school or home, one brings with one, embodied, certain quantities of different capitals. It is the physical embodiment of the different positions that the body has previously been able to inhabit. So one is always moving in and out of spaces carrying and sometimes increasing the value of different capitals. Although for some groups this may not be possible"* (1999: 214).

Legitimacy and value are both anchored on symbolic capital and thus *recognition* within given socio-spatial fields. Those who possess the 'right' capital within given socio-spatial fields strive for distinction from others, symbolically dominating those less capable of attaining such capital (Fowler, 2000). Chris was made redundant following his stroke, and his impairments made gaining and maintaining employment problematic:

> *…had a few interviews … things came up that my brain with the pressure of the interview couldn't do. The vital word or phrase - just couldn't do it. Came to nothing.*

The impact of failing to secure a job deeply impacted on Chris' sense of self-worth;

> **Chris:** *I was a valued person, the breadwinner in the family… But now I'm different,* ***I'm a second class person****… I felt that when I went to this reunion with my school people, I felt that there because a lot of them, doing brilliant, all got good jobs and all talking about it, and I didn't have much to say, I couldn't claim to know these things, you know* ***I felt my status had gone****… my income dropped to a third so there's lots of things other people can do that we can't. When we go shopping I always head straight to the out of date stuff… We used to go out for meals and things, I could do it and we had the money to pay for it but not now… I get pathetic little bit of satisfaction like buying nice food cheaply, finding a good deal with wine and enjoying that. It's pathetic.*

Chris' '*capacity to convert physical capital into other resources'* (Shilling, 1993: 139) had diminished with his disablement and associated difficulties in gaining employment. When disabilities remove the body's ability to assert its value in social spaces it is at risk of becoming devalued. The cultural capital and economic capital which Chris had previously gained from employment had been removed by his joblessness. Years spent accumulating skills and dispositions can come to be viewed as wasted effort when the body, in encountering certain fields, denies the habitus the ability to actualise itself. For Chris this loss of status had resulted in him identifying himself as a 'second class person' – as someone of less value. According to Robbins,

> *"…our social positions are only modified by our cultural tastes in as much as the cultural system assigns more value to some tastes than to others. We are not intrinsically altered by preferring Mozart over Morrissey… but the judgments of value made between our preferences within the cultural system affect our position within that system and have consequences for both our economic and our social position-taking"* (2000: 32).

For Chris the reduction in his in economic capital had diminished his ability to objectify and indulge his cultural tastes; meals out had been replaced by buying discounted food and wine. Chris' considered these new practices to be 'pathetic', a further embodiment of a second class, devalued status. Chris ultimately shifted from someone with access to the '*dominant symbolic'* (Skeggs & Loveday 2012) to someone without.

Of great importance to the embodiment process are symbolic representations of disability within the cultural milieu in which people with disabilities are '*othered*' and also physical spaces which exclude them or segregate them from their able-bodied counter parts. Public social spaces had become particularly problematic for Chris. Noisy environments exacerbated his aphasia which made socialising within such spaces challenging:

> *Any background noise, air conditioning, traffic on the street [makes things difficult] … I cannot go to noisy places, you know pubs and things. Tried it a few times, went in and came straight back out again... Even restaurants in the evening when I get tired – hard floors, doors scraping - can't do it.*

Such spaces became sites of exclusion for Chris. While such spaces are not designed to exclude people with impairments such as aphasia they also do not aim to *include*. The able body is privileged and assumed to be the norm. In Bourdieusian terms, those with disabilities remain the dominated within a cultural field that perpetuates an ableist doxa. Within this doxa the corporeal status of non-disabled people is favoured and dominant which presents a powerful pedagogical force and thus can become embodied within the habitus of both the non-disabled and disabled. It can be argued therefore that society (semi)consciously questions the legitimacy, *value* and competence of disabled bodies as they are so often excluded, segregated or go unconsidered. As Paterson and Hughes state:

> "*...the information that animates the world is dominated by non-disabled bodies, by a specific hegemonic form of carnality which excludes as it constructs"* (1999: 604 [cited in Edwards and Imrie 2003]).

Those who acquire disabilities and impairments are at risk of becoming '*overwhelmingly aware of the advantages accorded those who inhabit the unacknowledged "centre*"' (Galvin, 2003: 149). Chris had become aware that he could

no longer access the ubiquitous yet 'unacknowledged' advantages of able-bodiedness and thus absorbed and embodied the social position of the dominated, excluded and devalued. As Galvin notes:

> *'Although the loss of one's comparatively privileged subject position may be very sudden and momentous according to the particular nature of the accident, illness or injury, the overall summoning to a new level of identification is a gradual process whereby the doubts from within, the stares and snubs from without, and the lack of access to previously available social locations and resources erode one's prior claim to social acceptability'* (*ibid*).

Of course, the dominance held by able-bodied individuals is ultimately arbitrary. An individual's body is theirs from birth to death and despite the wear and tear it is put through the body is a mainstay of the self in both public and private quarters. It's apparent stability and ability to endure is, however, an illusion. The body is in fact a site of vulnerability and fragility and as McRuer states:

> *"[e]veryone is virtually disabled, both in the sense that able-bodied norms are 'intrinsically impossible to embody' and fully in the sense that able-bodied status is always temporary, disability being the one identity category that all people will embody if they live long enough"* (2006: 30).

Disability exposes the illusion of able-bodiedness and thus the body becomes a site of disquiet fuelled by an awareness of this illusion. This is something captured eloquently by Jenny Morris:

> *"[i]t is fear and denial of the frailty, vulnerability, mortality and arbitrariness of human experience that deters us from confronting such realities. Fear and denial prompt the isolation of those who are disabled, ill or old as "other," as "not like us"* (1991: 85).

There can be a simmering discomfort at being confronted with the fragility of existence for the able-bodied and an equal sense of discomfort for the disabled whose own body becomes a site of disquiet not only for themselves but for those around them. This issue is explored further below.

7.3.4: Bearing the Weight of a Lost (Feel for the) Game

The non-disabled individual, who is not accustomed to the company or presence of disabled individuals, can thus find such scenarios challenging as their habitus *may* not be equipped with the dispositions which would enable that person to know how to act and interact with disabled individuals. This is something which speaks to the inherent relationality within Bourdieu's approach. As Bottero notes:

> *"[m]any of Bourdieu's key concepts presuppose the predominance of a particular, very concrete form of network relation – homophily, a pattern of*

> *differential association in which agents are more likely to associate with those who are socially similar to themselves"* (2009: 406)[18].

This notion of homophily is present within Bourdieu's work and serves the purpose of underscoring how social groups recognise and interact within each other with ease due to shared understandings and practises, and also how groups seek to distinguish themselves from those they view as different. The concept of homophily, although not within a Bourdieusian framework, has been applied to social interaction between non-disabled and disabled individuals, for example, Brown *et al.* (2011) study of non-disabled high school students' '*behavioural intentions*' towards students with disability and Kulkarni's (2012) study of the role of homophily in influencing, often negatively, career advancement of people with disabilities. Such studies expose the role of homophily in the process of othering, or sectioning off of disabled individuals. As alluded to in the previous chapter family relationships represent a particular form of homophily in which mutual understandings of one and another are developed through an extensive investment of time, physical closeness within shared private space. As argued within the previous chapter the family can represent a deeply woven shared history and as such family members can develop an instinctive empathetic understanding of each other; they have, to some extent, embodied aspects of each other. Yet, when one individual becomes disabled or acquires impairments this

[18] Bottero provides an interesting critique of the role of homophily within Bourdieu's work pointing out that acts of social interaction are not fully developed within Bourdieu's approach. However, part of this critique is grounded in a reading of Bourdieu's early work which explicitly sought to explore and expose the reproduction of dominance. Furthermore, just because Bourdieu does not fully explore the minutiae of social interaction within his own work does not mean that the thinking tools offered by Bourdieu cannot themselves be utilised creatively in such an exploration by others. There comes a point where the theorist and the theory must be separated.

understanding breaks down and homophily underpinning the relationship becomes threatened:

> **Chris:** *[the stroke has] damaged our relationship really. She gets very frustrated ... My wife gets impatient with me, I'll be doing something and she'll be speaking and I'll say "what did you say?" I can't recall the first three or four words and she'll get angry because she has to repeat herself and this is after 11 years ... she tends to overdo it by speaking more loudly. The same thing happens again and again… she does sometimes say "oh what if, it's such a shame". She gets irritated because we can't go out socially because of the noise and things.*

Chris' discussions regarding his relationship with his wife were often framed around her frustration at his impairments and a fundamental change in their interactions. As mentioned within the pervious chapter, the habitus enables a sense of orientation - a 'feel for the game'. For Chris and his wife their 'feel for the game' with one and another was built, *in part*, upon an able-bodied homophily. Chris' body however breaks down this taken for granted sense of similarity and understanding: their '*taken-for-granted harmonies had been disturbed*' (Lawrence & Kinn, 2013: 591). This is similar to Kelly's (2010) study of AIDS dementia discussed within the previous chapter. Within Kelly's study a new 'feel for the game' began to develop between family members enabling new patters of relating. Chris and his wife had developed a new pattern of relating, however this pattern was often layered with tensions, the root of which lay within Chris' body and its disruption of their historically interwoven

understandings of one and another. Despite Chris' wife's complicity in creating this tension (e.g. acts of frustration and impatience, speaking loudly as opposed to simply repeating) Chris' body bore the weight of this lost feel for the game. As such not only was Chris' body delegitimised and excluded from the world of employment and the status, capital and distinction this provided, it was also a site of disquiet and the cause of 'damage' between he and his wife. Chris' relationship with his wife thus added another layer onto the embodiment of a devalued identity.

7.3.5: Change in the Site of Conatus for a limited Illusio

Within the previous sections of this chapter, the losses associated with disability have been explored, however illness does not necessarily equate only to loss. Chronic illness can result in a reinvigoration or a continuation of the pre-illness or pre- impairment lifestyle. According to Williams (1984), for example, narrative strategies can be utilised by those with chronic illness to both make sense of the illness within their own personal biographies and to '*reaffirm the impression that life has a course and the self has a purpose*' (1984: 179). According to Frank (1993) acquiring illness or impairment can result in a sense of clarity and an opportunity to make positive changes. Despite Chris' assertion that he was a 'second class person' there were also positive changes within his life:

> *I was always a little bit too ambitious so I've diverted my efforts into sporting things … I started doing the exercises in my house then going for walks and eventually back to jogging. So the physical side… my ambitions have gone into that – I'm champion for cycling for people in my age group.*

Things like that … I never would have had time for this before as I constantly worked

Prior to his stroke Chris' job was the key part of his life. In a Bourdieusian sense Chris' job was a site of conatus. Due to his impairments the dispositions which enabled him to augment his social being though his job were phantomised. Or as Chris put it himself; *this [gestures his hands to head]? Disaster.* Engaging in sports created a new site of conatus where Chris could perpetuate his being and achieve success. In this context Chris was able to accumulate and cultivate physical capital which had the potential to offset the reduction in his cultural capital. This is reminiscent of Wainwright and Turner's ballet dancers who offset their diminished physical capital with their embodied cultural capital. As well as a change in the site of conatus this also suggests a reinvigoration of the illusio or social libido. The illusio relates to a libidinal investment in something that provides meaning and value to one's life.

However, Chris' libidinal investment in sport did not appear to fully offset his sense of 'devaluement' as he referred to his sporting accomplishments as '*pathetic*'. This suggests that offsetting a lost ability with the perpetuation of another may only provide a limited consolation. Again, this relates back to the notion of phantom dispositions and the enduring memory of able-bodiedness.

7.4: BETWIXT & BETWEEN: HABITUS & HEXIS IN LIMINALITY

Our sense of self typically changes very gradually over the life course; we certainly do not have the same self-conceptualisation in our teen years as we do in our 50s and 60s. While we have the capacity to be reflexive regarding the changes in ourselves, possibly when reminiscing with old friends or when telling old family stories over Christmas lunch with parents and siblings, our awareness of our continual but subtle change is not something we are fully conscious of every day of our lives. This produces the sense of an enduring and stable personal and public identity. Key life events are anchoring points to changes within one's life circumstances; starting your first job, leaving home and going to university, falling in love, buying a house and having children. Each of these events causes a life disruption and results in changes in priorities and actions in the present as well as plans and expectations for the future. The disruption is, for the most part, short-lived and the adjustment period ephemeral. Life, as it were, goes on.

For Caitlin and Chris the life disruption they experienced was not an external factor (like buying a house) which altered circumstance but a highly personal and internal disruption to the body. The concept of phantom dispositions exposes the frustrations and anxieties that can be caused when the habitus is out of sync with the body. The memory of being able-bodied remains incredibly strong and the dispositions learned when the body lacked impairments remain within the habitus yet cannot be enacted bodily. This makes adjusting to impairments problematic as the habitus contains dispositions which are in conflict with each other and with the body. The embodiment of a devalued identity reflects a similar problem however the lost sense of ease with

the body is underpinned by the overwhelming knowledge of the advantages and social acceptance of their lost able-bodiedness. The potential to absorb disability into the individual's biography represent a challenging endeavour. This is because the habitus becomes problematised, moored between two worlds of the pre-stroke self where historic dispositions were formed, and the post-stroke self, where new dispositions are required and others are phantomised. One of Bourdieu's thinking tools, hysteresis effect, touches upon this phenomenon. The hysteresis effect can be thought of as the '*dislocation of habitus'* (Hardy 2010: 131). As Bourdieu explains:

> *"…the practices that are generated by the habitus and are governed by the past conditions of production of their generative principle are adapted in advance to the objective conditions whenever the conditions in which the habitus functions have remained identical, or similar, to the conditions in which it was constituted… The presence of the past in this kind of false anticipation of the future performed by the habitus is, paradoxically, most clearly seen when the sense of the probable future is belied and when dispositions ill-adjusted to the objective chances because of a hysteresis effect … are negatively sanctioned because the environment they actually encounter is too different from the one to which they are objectively adjusted"* (1990b: 62).

What Bourdieu means by the hysteresis effect is, ultimately, a disconnection emerging between habitus and field. This concept does contain some similarity with the above discussion of a field phantomising a disposition or set of dispositions, however it fails

fully account for the phenomenon of being between the worlds of the able-bodied and disabled. This is because for Chris and Caitlin their habituses were not encountering a *field or fields* with which they not accustomed; many of the fields they manoeuvred within remained predominately unchanged. These fields were also sites where their historical dispositions had been formed. When within these fields the anticipation of the future performed by the habitus remains in the form of historical dispositions; however their abilities to enact practices, previously embodied as appropriate practices within these fields, falter due to their impairments as Chris stated:

> *…my wife's friends… some of them, very hospitable. I just can't reciprocate. Either gatherings are too noisy or I feel embarrassed, them being such good hosts and we, I, can't reciprocate… Family gatherings, I just can't keep up with the pace. I used to be a jovial person. Little bits come out but I can't. I get very withdrawn and do my own thing…*

For Chris his failed attempt to maintain behaviours and practices he thought to be appropriate within these circumstances appeared to result in embarrassment and exclusion. While this exclusion is, on the surface, Chris' choice such comments expose the embodiment of the 'rules of the game' within such socio-spatial fields and the sense of shame experienced when one is no longer fully able to 'play the game'. Caitlin also referred to the demands of a field in her discussions of the façade she felt she had to maintain. Therefore the findings here, while suggestive of hysteresis effect, do not fit within this concept; it is not the field which has changed but the body, or more precisely, the body's ability to actualise the practices deemed *appropriate* within

certain files. In other words the habitus and hexis are out of sync not the habitus and field. This should not be viewed as a return to the biomedical model, however, as it is not simply a case of bodily impairments restricting an individual's behaviours. The demands of particular fields, the habtisues of those within these fields and the embodied knowledge of the expectations and demands of these fields within the disabled individual's habitus all play a role. Compounding this is the sense of loss and mourning associated with absent capabilities. As such neither the social nor biomedical model are sympathised with here.

Rather than Chris and Caitlin experiencing the hysteresis effect, their habituses are, to borrow terminology from Victor Turner, betwixt and between; lodged within a state of liminality. In *Liminality and Communitas* (1969), Turner defines liminal individuals as '*neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremony*' (1990 [1969]: 147). Their social condition is, therefore, '*a confusion of all the customary categories'* (Turner, 1967: 97 [cited in Willett & Deegan 2001]). As the liminal individual is neither one thing nor the other they become invisible persons. Moreover, they become persons which generate disquiet among others; '*it is a paradox, a scandal, to see what ought not to be there'* (Turner, 1967: 98 [cited in Willett & Deegan 2001]). It should therefore be unsurprising that there have been numerous studies which utilise the concept of a liminal state to explore the experience of individuals with disabilities (Deegan, 1975; Murphy, 2001; [1990]; Nicolaisen, 1995; Devlieger, 1995). Stroke survivors with enduring disabilities cannot be cured nor are they necessarily ill. Such individuals do not fit neatly into categories of wellness or sickness and, therefore, can be viewed as existing in an

ambiguous state; a liminal state. For Caitlin and Chris the state of liminality had been caused by the habitus becoming *'divided against itself'* (Bourdieu, 1999: 4) as the historical dispositions of the habitus had been formed across years, or even a life time, of able-bodiedness and thus their bodies and habituses were now forced to recondition themselves. However, this reconditioning was problematised by phantom dispositions and an embodied sense of devaluement.

To reiterate the quote from Turner above, when in a state of liminality the individual is between *'positions assigned and arrayed by law, custom, convention, and ceremony*'. As outlined above the position of able-bodiedness is one of privilege while the position of the disabled body is one of exclusion, pity and fear. The habituses of Chris and Caitlin contained dispositions, embodied experiences, of each position. As such their identities, sense of self and 'feel for the game' become imbued with ambiguity. The liminal state is meant to come to an end once the individual has transitioned from one state to another and therefore the individual is no longer inculcated with ambiguity. Moreover, within Bourdieu's conceptualisation of the hysteresis effect the habitus is, over time, meant to 'catch-up' with the change within the field. Caitlin's stroke occurred 4 years prior to her interview and Chris' 12 years prior to interview yet they both remained stuck between two embodied states. This suggests that the habitus of a stroke survivor my struggle to adapt or transition. Much of the dispositions of the habitus are acquired without conscious awareness, perhaps becoming particularly and suddenly aware of the body and the external environment due to acquired impairments disrupts the habituses ability to adapt.

7.5: SUMMARY & IMPLICATIONS FOR PRACTICE

Exploring Bourdieu's theoretical toolkit via empirical data was a central concern of this thesis. This exploration has exposed that, despite the body resting at the heart of Bourdieu's work this theoretical toolkit cannot, without creativity, account for the potential for the habitus and bodily hexis to be out of sync. Yet this phenomenon was exposed during the analysis of empirical data. In order to attempt to explore and explain the process whereby embodied dispositions can no longer be actualised via the bodily hexis Bourdieu's concept of dispositions has been adapted creating a new thinking tool; phantom dispositions. This adaptation has the potential to play a crucial role in bringing the body to the fore within analysis of disability, not in a manner which suggests the disabled body requires correction but in a manner which enables an exploration of the very real frustrations created by impairments.

By exploring the empirical data through the lens of embodiment and utilising Bourdieusian thinking this case study has also unpicked some of the processes whereby acquiring impairments can lead to the development of a devalued identity. This conceptualisation again brings the body, and the powerful symbolic value the body can hold, to the fore. As outlined within this chapter, and toward the beginning of this thesis, the social world is filled with information and symbolism which devalues disabled bodies. This information is embodied both before and after impairments are acquired making the body and the self a site of disquiet, ambiguity and ambivalence and ultimately of symbolic violence. Adding to this are the nuanced ways in which social fields can exclude and devalue disabled bodies. This can be due to the nature of the environment but also due to the attitudes of others within those environments.

The phantomising of dispositions and the embodiment of a devalued identity can result in the habitus of the stroke survivors becoming moored in a liminal state. As dispositions are formed and mutate across the life course, knowledge of able-bodiedness conflicts with the new disabled bodily status. Both Chris and Caitlin had come to embody particular dispositions characterised by ambiguity about the self and frustrations regarding the body which were in direct conflict with their prior selves. Their biographies were not disrupted; they were betwixt and between two worlds.

7.5.1: Implications for practice

Both Caitlin and Chris faced on-going challenges regarding living well with their impairments. These challenges were compounded by individuals within their social network. The findings presented within this case study add further backing to the recommendations presented within the previous chapter which highlighted the need for increased access to clinical psychology services for both stroke survivors and family members. However, the recommendation of mindfulness services is perhaps more pertinent here. Mindfulness interventions have been shown to be beneficial for chronic pain, anxiety, and depression (Cassidy *et al.,* 2012; Hofmann *et al.,* 2010; Hodge *et al*., 2013; Hargus *et al.,* 2010; Segal, Williams & Teasdale, 2012). There is increasing interest in the potential of mindfulness services for stroke survivors (Johansson, Bjuhr, & Rönnbäck, 2012; Lawrence *et al.,* 2013) with recent systematic review findings suggesting such services can provide beneficial assistance with psychological, psychosocial, and physical problems faced by stroke survivors (Lawrence *et al.,* 2013). As such mindfulness could potentially be advantageous in enabling stroke

survivors, such as Caitlin and Chris, to cope with the physical and psychosocial frustrations they continued to face in the years post stroke event.

The findings also reiterate the need for employers to be given greater guidance and training regarding the needs of stroke survivors, not only at work but also during the recruitment process. However, the overarching problem faced by stroke survivors appears to be societal attitudes to disability which can impact on their sense of self, relationships and other aspects of life. This task is one which disability campaigners have been fighting for decades yet remains hugely problematic. As was made clear within the introductory chapter of this thesis, society has a long way to go in tackling this issue.

CHAPTER 8: CONCLUDING REMARKS

8.1: INTRODUCTION

This thesis began with two key aims. The first aim was to explore the experiences and perceptions of long-term, community dwelling stroke survivors. The second key aim involved the use of, and exploration of, the theoretical toolkit offered by the work of Pierre Bourdieu. The reasons for utilising Bourdieu's thinking tools and applying Bourdieusian thinking were due to the onus on the role of the body and embodiment within Bourdieu's work.

Off the back of these aims the following research questions were posed:

(1) *What are the experiences and perceptions of those living with stroke in the long-term?*

I. *How do stroke survivors absorb the experience of stroke and associated impairments into their embodied identities?*

II. *Does this process of embodiment reconcile the pre and post-stroke self?*

III. *Do long-term stroke survivors experience on-going challenges in their daily lives?*

(2) *Can Bourdieusian thinking enable an in-depth understanding of the embodiment process for those living with stroke in the long-term?*

II. *Are the contents of Bourdieu's theoretical toolkit robust enough to explore and explain the experiences and perceptions of long-term*

stroke survivors or does it require theoretical adaption and expansion?

The purpose of this chapter is to discuss whether these questions have been answered and what these answers are. Following this discussion the limitations of study will be reflected up on before future avenues for research are proposed.

8.2: RESEARCH QUESTION ONE: What are the experiences and perceptions of those living with stroke in the long-term?

This overarching question is best explored by answering the more specific subsidiary questions.

- *Firstly, how do stroke survivors absorb the experience of stroke and associated impairments into their embodied identities?*

The findings presented within both Chapter 6 and Chapter 7 expose that the experience of stroke becomes embodied, predominately via the emotions experienced as stroke survivors negotiate their social capital, manoeuvre within socio-spatial fields, and also through the very real experience of limitations and frustrations placed upon them by their acquired impairments. It is not merely the encounters and experiences within the social world, or the experience of impairments themselves which influence embodiment but the emotions embedded within those experiences. For the stroke survivors within this study these emotions were nuanced and founded not only with present experiences but also within their own personal histories; their habituses. For example, the interactions with family members were characterised by sympathy, ambivalence and guilt. Through shared interwoven histories families can represent a

deeply embedded form of social capital laden with emotions which foster caring and sympathetic practices. This is in keeping with the literature on stroke in which families are known to play a key role in the provision of emotional and practical support (Bugge *et al.,* 1999; Bhogal *et al.,* 2003; Pierce *et al.,* 2006). Such loving dispositions are cultivated over time and are also the source of the emotions of guilt and sympathy. However, the changes in social role, and the potential for family member's behaviours to become oppressive, meant that these relationships also became sites of ambivalence and frustrations.

Emotions also played a key role in the development of devalued identities. Key emotions here were embarrassment and shame. These feelings were present within familial interactions where stroke survivors would self-stigmatise, family members would avoid acknowledging disabilities or the stroke survivors would put on a façade of able-bodiedness. As such symbolic violence played a crucial role within the embodiment process as stroke survivors accepted the negative connotations of disability within society as situated within their own bodies.

Further emotions experienced rested at the heart bodily impairments. The stroke survivors, despite the length of time since their strokes had occurred, still spoke about their impairments through the lens of grief, loss and frustration. However, they could find these feeling were delegitimised by family members. Again this could perpetuate the embodiment of ambivalence. As Jenny Morris argues the grief experienced by people with disabilities is not a '*failure to come to terms'* but a '*sane response'* (1991:

9, 10). At the heart of this process was a lack of understanding from others regarding the experience of being disabled. Bodies can be taken for granted by those without disabilities however becoming disabled breaks down this taken for granted experience of both the body and social world. Acquiring a disability results in the '*erstwhile taken-for-granted world of everyday life*' becoming '*a burden of conscious and deliberate action*' (Bury, 1982: 176). This embodied experience is not something an able-bodied individual can truly understand and as such the stroke survivor and their family members can lose their innate understanding of each other. The fact that grief remains an ongoing experience for stroke survivors many years after their stroke exposes not only that the loss of capabilities is not something one can just get over, but also that reconciling disabilities with the historical sense of self is potentially an impossible struggle.

Families were not the only sites of tension. Places of work could also create problems for the stroke survivors. The key issues experienced were due to a lack of understanding and accommodation of impairments which made working become stressful. Work environments could lead to the stroke survivors failing to perform to the top of their capabilities. This echoes findings elsewhere which suggest that returning to work and maintaining work remains problematic (Corr & Wilmer, 2003; Gilworth *et al*., 2009; Treger *et al.,* 2007; Gilworth *et al.,* 2009; Alaszewski *et al.,* 2007; Different Strokes, 2002). However, not only did this create a sense of stress but also of shame and embarrassment. This sense of shame again reflects the embodiment of the ableist stereotypes within society which portray disabled bodies as less capable (Edwards & Imrie 2003).

As families and work colleagues can lack the ability to understand the embodied meaning of disability being able to interact with others with disability might appear to offer some solace. However, the stroke survivors within this study appeared to shun the idea of socialising with fellow stroke survivors and those who did attend stroke clubs found that these groups did not offer the kinds of support expected or hoped for. Homophily represents a key aspect of the Bourdieusian understanding of social groups. The findings of this study suggest that the potential sense of mutual understanding presented by fellow stroke survivors failed to appeal. This however does not disprove the idea of homophily but says more about the sense of unease those with acquired impairments can have towards other people with disabilities. This exposes that the ableist attitudes towards disability, in which it is viewed as something to fear and pity, is not necessarily reduced by acquiring impairments but can actually be accentuated. Jenny Morris states:

> *[O]ur disability frightens people. They don't want to think that this is something which could happen to them. So we become separated from common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity* (1991: 192)

Within much of the literature on disability the view that the able-bodied fear and pity the disabled 'other' is often cited. However, the findings of this study suggest that

those with acquired impairments can remain fearful of other disabled people due to an innate and deeply corporeal fear of becoming more impaired and more disabled. The company of other disabled people does not offer comfort but anxiety. This exposes, not only that disabled individuals are capable of ableist beliefs, but that such beliefs perform symbolic violence by proxy.

- *Secondly, does this process of embodiment reconcile the pre and post-stroke self?*

The case study and thematic analysis expose the insidious processes whereby stroke survivors can embody a devalued identity in which their bodies become illegitimate within certain social spaces. The processes in which the individual comes to embody such an identity are produced by a combination of attitudes, the nature of socio-spatial fields and due to the nature of impairments themselves. This theme reveals that the social world is indeed within the body as much as the body is within the social world. The disabled body becomes the bearer of societal weight and the weight can be considerable and uncomfortable to bear. This discomfort is worsened by the knowledge of what life was once like before such a burden was carried. Grief regarding lost abilities, no matter how minor they might appear, is thus a continual and legitimate emotion. Furthermore, the case study and the development of the notion of phantom dispositions exposed that the experience of impairments creates a tension within the body as the habitus and bodily hexis become somewhat out of sync. Both of these themes reveal that the habitus of the stroke survivor can become trapped in a liminal state as identity is fractured between the historic and the present where accepting the present means accepting a life of limitation and loss.

- *Thirdly, do long-term stroke survivors experience on-going challenges in their daily lives?*

The short answer to this question is yes. The challenges faced by the stroke survivors were many. Negotiating their social capital was often fraught with tensions. Gaining and maintaining employment presented, not only practical challenges but could also lead to anxiety and an embodied sense of shame regarding impairments. Stroke survivors could lose their independence due to both impairments and the behaviours of others. However, possibly the biggest challenge faced by the stroke survivors was being able to reconcile their able bodied past with their disabled present.

Implications for practice

The experience of being a stroke survivor is both a catastrophic corporeal experience and a complex and challenging social experience characterised by ambiguity about the self and ambivalence regarding socio-spatial fields. As such long-term stroke survivors, as *The Stroke Association* (2012) suggest, struggle to recover. These findings back calls for improved access to clinical psychology services. However, in Scotland, where this study was based, only a third of stroke units have access to clinical psychology services (*The Stroke Association,* 2013). As such greater funding and raising awareness regarding the need for such services is required. Access to other services, such as self-management or mindfulness programmes designed to assist individuals to live well with their condition should be given greater consideration for long-term stroke survivors. Self-management and mindfulness programmes for stroke survivors are currently focused on the rehabilitation phase. As Lawrence *et al.* (2013) and Lennon, McKenna and Jones (2013) report more evidence is required regarding the benefits of

mindfulness and self-management for stroke survivors however the evidence available is positive.

8.3: RESEARCH QUESTION TWO: Can Bourdieusian thinking enable an in-depth understanding of the embodiment process for those living with stroke in the long-term?

As the systematic review presented in Chapter 3 suggests this study is the only, or one of very few, to explicitly utilise Bourdieu within the context of stroke. Examining stroke through the lens of embodiment provided useful insights into the deep and nuanced ways in which social interactions and socio-spatial fields can influence sense of self as well as practice and action. Bourdieusian thinking proved to be a profitable approach for examining the experiences and perceptions of stroke survivors, exposing that the ways in which the individual becomes disabled are not merely social or biological but a matter of complex interplay between both structure and agency. The use of Bourdieu also exposed the role of the body as a bearer of value. As Shilling explains, within Bourdieu's sociology the body is '*a possessor of power, status and distinctive symbolic forms integral to the accumulation of various resources'* (1993: 124). The empirical data within this study exposed that disabled bodies could become devalued, no longer able to access the 'dominant symbolic' (Skeggs & Loveday 2012) of able-bodiedness.

- *Are the contents of Bourdieu's theoretical toolkit robust enough to explore and explain the experiences and perceptions of long-term stroke survivors or does it require theoretical adaption and expansion?*

The process of examining data through a theoretical lens provided an in-depth understanding of both the theory and phenomena. The exploration of social capital and manoeuvring within socio-spatial fields provided the opportunity to explore the role of emotion within Bourdieusian thinking and in turn exposed the powerful, almost pedagogic force, of emotion in the process of embodiment. Reay (2000, 2004) has accused Bourdieu of failing to account for emotions. However, emotions are in fact an ever present subtext within many of the key Bourdieusian thinking tools such as symbolic violence and bodily hexis. As the process of analysis utilised within this thesis was guided by the principles of adaptive theory, whereby empirical data and theory were in continual conversation, Bourdieu's work needed to be given a deeper consideration. This process exposed the vital role of emotions within the toolkit which could well be missed, particularly when only habitus, capital and field are considered. By exploring lesser used concepts, such as conatus and illusion, for example, the researcher can metaphorically scratch the surface and expose the more subtle aspects of Bourdieu's work.

The theme of devalued identity exposed within this study is also tied-up the role of bodily emotions in shaping the self. This theme was developed through examining how others have applied Bourdieusian thinking as opposed to from the thinking tools offered by Bourdieu alone. This accentuates the view of Bourdieu's work as a method of thinking as opposed to a strict set of theoretical tools. In other words it exposes the potential of thinking creatively with Bourdieu. Bourdieusian thinking offers more than the mere transcendence of the structure and agency dualism. Within this frame work the social production of inequalities can be examined and understood in relation to

the process of embodiment and bodily dispositions. This bodily focus is important as it can redress the manner in which the body can become a silent witness within disability and stroke research. Bodies are thus brought back in to analysis and understanding.

However, Bourdieu's thinking tools were tested by the empirical data. Despite the body resting at the heart of Bourdieu's work there appears to be a lack of a conceptual tool which truly accounts for the possibility for the habitus and bodily hexis to be 'out of sync'. The potential for Bourdieu's toolkit to fall short was anticipated. As Inglis states; '*we cannot reasonably expect any model of any phenomena to capture fully all the possible permutations of such phenomena'* (2013: 319). It should be accepted that when thinking with Bourdieu one may also have to think '*beyond or even against Bourdieu*' (Atkinson 2010: 16). In order to account for the phenomenon of the habitus and bodily hexis becoming disconnected an adaptation was required. This adaptation was 'phantom dispositions'. Within Bourdieusian thinking habitus is often favoured and used exhaustively, although often shallowly. By bringing the role of dispositions to the fore there is the potential to explore, in more depth, the tensions and problems which can arise within the body as a result of impairment. Furthermore, while Bourdieu offers the hysteresis effect to account for moments where the habitus can be out of sync with a field, or matrix of fields, there is no explanatory tool which captures the *impact* of the a habitus being problematised by being between two states of being. In order to offer such an explanatory tool the notion of the habitus being lodged in a liminal state has been presented. This conceptualisation means to highlight both that for stroke survivors identity can be tenuous and also that the historical dispositions of the habitus can prove to be a powerful force as they leave the stroke survivor achingly

aware of what being able-bodied *felt* like. Disability can perhaps fail to live up to the standard to able-bodiedness.

8.4: LIMITATIONS

The methods utilised for this study involved a postal survey to provide a sample for the interview phase. This survey could have been utilised more to inform the analysis, as a standalone aspect of the research or fully integrated with the interview data. However, the purpose of this study was to understand the experiences and perceptions of stroke survivors and gather data on the process of embodiment. The survey fulfilled the role of providing a sample for purposive sampling and the data could be utilised for secondary analysis. However, the survey itself also contained limitations. In retrospect the length of the survey was potentially too long. As the BOSS scale contained questions on mobility, communication, cognition as well as questions of social relationships and the ability to engage in leisure activities this scale could have been utilised to cover the majority of information sought for the process of sampling. However, the purposive sampling process was meant to enable the selection of interviewees who represented the diversity within the population of stroke survivors. The methods utilised still produced a varied sample in terms of age, socio-economic background, impairments and in terms the social capital held and as such the process of purposive sample was ultimately fit for purpose.

By focusing on Bourdieusian thinking the analysis of the data could be deemed as somewhat blinkered and perhaps missed salient themes which a pure grounded theory

approach may have produced. However, the aim was in part to use the data to explore the theory. This enabled an in-depth exploration of the role of emotion in embodiment and also provided the opportunity to develop a theoretical adaptation, both of which provided useful insights into the manner in which the body can become out of sync with the historical sense of self. Just because the data was not necessarily allowed to 'speak for itself' does not mean the findings are less trustworthy.

As this was a small qualitative study the findings are not generalizable. However, this is a common pay-off within qualitative data where generalizability is compromised for in-depth understanding. While quantitative methods can provide generalizable results they tend to use pre-conceived categories and therefore, might not produce a theories or findings that closely relate to the participant's subjective experiences (Bogdan & Biklen, 1998). The aim of this thesis was to achieve `depth' rather than `breadth' (Blaxter, Hughes & Tight, 1996: 61) as thesis sought to explore personal experiences and also to explore theoretical concerns. The research has been able to illuminate the nuances and complexities associated within the personal experiences and perceptions of living with acquired impairments. Such findings may not be generalizable, however what these finding add should not be dismissed. Evidence is ultimately cumulative and the findings presented here play a role in adding to the growing body of evidence which highlights the long-term needs stroke survivors encounter, and also the potential injustices those with impairments and disabilities face living in a society which is still not fully equipped to understand, accommodate and accept them.

The approach taken within this thesis has also offered the opportunity to investigate the potentially crucial role emotions can play within Bourdieusian analysis and also in the process of embodiment. By synthesising Bourdieu's use of emotions within his work with empirical data this thesis can offer some guidance as to how future researchers might incorporate emotions in future Bourdieusian analysis without misconstruing emotions as capital as in the case of Diane Reay's work (Reay 2000, 2004). This research also offered the opportunity to expand upon the concept of dispositions. By exploring the adaptation of phantom dispositions via cognitive impairments (as opposed to physical ones) this thesis highlights the deeply embedded yet hidden connections between body and habitus and the frustrations a break in these connections can cause. This adaptation also exposes the role the social, external world can play in preventing individuals from realising their own capabilities in practice. As such this adaptation could be utilised in future research to explore other medical conditions were there impairments play a key role in phantomising dispositions. However, this concept could also be used to explore the processes of disembodiment which occur in situations of high stress such as occupational stress, bereavement, or even post-traumatic stress where the habitus can become 'divided against itself' and thus realising historical dispositions in practice becomes problematised. As such, while this thesis could have explored the data in a more purely inductive approach, utilising Bourdieusian thinking has been profitable and while the qualitative approach utilised means that the findings are not generalizable this not mean that they do not offer fruitful forms of understanding.

8.5: FUTURE RESEARCH

It is clear that stroke survivors and their families experience considerable burden due to the alterations within relationships caused by stroke. Stroke survivors can struggle with feelings of loss and grief and also be trapped between two identities. As such research seeking to explore the potential benefits of clinical psychology, self-management and mindfulness programmes for long-term stroke survivors and their families could prove fruitful. Programmes which are family orientated would also be of great benefit to enable increased understanding of the subjective experience of impairments for family members. Therefore, greater interventions based research into these programmes, with a focus on the long-term experience, could prove crucial for enabling a more positive long-term experience for those living with stroke.

Stroke support groups appeared to be a problematic concept for the stroke survivors in this study with some reporting that these groups failed to meet their needs. Comprehensive research into the benefits of these groups could help to identify key ways in which such groups could be supported by both state and volunteer services to help them deliver greater support to community dwelling stroke survivors.

Finally, the findings from this study were fruitful in exploring the process of embodiment within the context of disability. Future research could further explore the concept of phantom dispositions within other patient groups, such as Alzheimer's, to explore its usability and potential to enhance understanding of the corporeal experience as well as the social experience of lost capabilities.

APPENDICES

APPENDIX 2: ACCOUNTING FOR 'SOCIAL CAPITAL' OUTWITH BOURDIEU

The Bourdieusian understanding of social capital is not the only conceptualisation of this term. If one were to explore the term out with Bourdieusian theory it would become apparent that there is no single definition of social capital. The concept's popularity has steadily increased over the last twenty years and as a result the term is '*proliferating meanings and provoking contests*' (Farr 2004: 6). The three classic conceptualisations of the term come from Bourdieu and from the work of James Coleman, an American sociologist, and Robert Putnam, an American political scientist. While the usages of social capital offered by Bourdieu, Coleman and Putnam have some commonalities there are differences and each of these conceptualisations are distinct. As this thesis sought to explore the experiences and perceptions of long-term stroke survivors living in the community the conceptualisation of social capital taken forward within this thesis is that offered by Bourdieu. However, as the term 'social capital' has become common place across social and political science literature, particularly within public health literature, it is worthwhile considering and critiquing each of these usages. As such the purpose here is to present such a discussion.

SOCIAL CAPITAL

While there are numerous definitions of social capital a simple outline is possible. The summary definition below, by Field, gets to the point:

> '*By making connections with one another, and keeping them going over time, people are able to work together to achieve things that they either could not achieve by themselves, or could only achieve with great difficulty.*

> *People connect through a series of networks and they tend to share common values with other members of these networks; to the extent that these networks constitute a resource, they can be seen as forming a kind of capital*' (2007: 1).

From the excerpt above one can conclude that social capital is to do with the networks and relationships formed within society which can amount to a resource or as Robert Putnam asserts; '*social networks have value'* (Putnam 2000: 19).

While social capital is currently in vogue, the concept is not new. Some authors argue that the concept's heredity rests with Durkheim, Marx, Tocqueville, Simmel, and Weber (Baum & Ziersch 2003, Adam & Rončević 2003). The first use of term 'social capital' has been linked to Lyda Judson Hanifan and John Dewey (Farr 2004). Despite deep foundations considered uses of the term were sparse until the late 1980s and 1990s.

In order to get at these varying definitions and also the possible reasons for the term's popularity the work of three key social capital theorists should be considered; Pierre Bourdieu, James Coleman and Robert Putnam who can be marked out as the 'social capital classics' (Field 2007:40).

PIERRE BOURDIEU

Bourdieu's notes on social capital emerged through his work during the 1960s to 1970s taking shape by 1980s/90s (Baron, Field & Schuller, 2002:3) for example within *Le capital social: Notes provisoires* [Social Capital: preliminary notes] (1980). However,

the most often examined and quoted of his writings regarding social capital come from the book chapter *The Forms of Capital* within the *Handbook of Theory and Research for the Sociology of Education* (Richardson 1986). He was one of the first to offer a contemporary analysis of social capital (Portes 1998) but had little immediate impact in the English-speaking world, possibly due to Bourdieu's somewhat impenetrable writing style. Bourdieu's definition of social capital has been outlined within Chapter 2 of this thesis and thus is it unnecessary to reiterate it here. Therefore, Coleman's understanding is outlined before Putnam's is considered.

COLEMAN: SOCIAL CAPITAL AS A FUNCTIONAL MECHANISM

James Coleman brought social capital into the mainstream of sociology in the United States of America (USA) (DeFilippis 2001). Coleman's interpretation developed from research on sophomores in American high schools. For Coleman social capital can benefit the marginalised and poorer communities, not just the upper classes. In *Foundations of Social Theory* Coleman states;

> *'[S]ocial Capital is defined by its function. It is not a single entity but a variety of different entities having two elements in common: They all consist of some aspect of social structure, and they facilitate certain actions of individuals who are within the structure'* (Coleman 1994: 302).

Here social capital is intrinsically functional; a mechanism that facilitates the activity of people and groups/institutions. The association between social capital and access to resources in this definition is causal not 'circular' as with Bourdieu (Baron, Field & Schuller 2002). One's social relations can produce useful capital, according to Coleman,

by creating trust and obligations, leading to 'channels for information' and established a set of norms (Baron, Field & Schuller, 2002: 6). It should be understood that, while Bourdieu conceptualisation of social capital can be viewed as neo-Marxist or 'cultural materialist', Coleman's approach is based in 'rational choice sociology'.

Rational Choice sociological approach

This theoretical perspective maintains that people are typically individualistic, acting for their own interests without considering others. Such a theory has a major problem; if we are intrinsically self-serving how are we able to cooperate? Social capital provided Coleman with an explanation; we work together for our own advantage (Field 2007). Coleman's use of social capital is also quite pragmatic as he states social capital;

> *'…is fungible with respect to specific activities. A given form of social capital that is valuable in facilitating certain actions may be useless or even harmful in others'* (Coleman, 1994: 302).

Therefore, social capital can be advantageous, futile or even detrimental depending on the circumstance. For Coleman, social capital is a functional '*by-product of activities engaged in for other purposes*' (Coleman, 1994: 312) rather than an intentional product, as Bourdieu argued it *could* be. This lack of intentionality is somewhat dubious, while Coleman acknowledges that social capital could have negative consequences, it is generally viewed as a good thing existing for mutual advantage which, simply occurs providing the norms we live by in order to cooperate. As DeFilippis asserts, it becomes '*morally neutral … neither desirable nor undesirable; it*

simply allows actions to take place by providing the needed resources' (DeFilippis, 2001: 784).

While Coleman's interpretation is accessible, it is also 'fuzzy' (DeFilippis, 2001: 784). Portes argues that Colman '*opened the way for re-labelling a number of different and even contradictory processes as social capital'* (1998: 5) and thus started the '*proliferation'* of the term *(ibid*). Coleman uses social capital as an umbrella term; social capital becomes;

> *'some of the mechanisms that generated social capital (such as reciprocity expectations and group enforcement of norms), the consequences of its possession (such as privileged access to information); and the "appropriable" social organization that provided the context for both sources and effects to materialise'* (Portes, 1998:5).

In effect, Coleman's conceptualisation of social capital is not a key aspect of social connections, but all aspects.

Another criticism of Coleman's social capital is his emphasis on 'dense ties'. Coleman saw the family as the core form of 'primordial' social organisations (relationships established at birth) and contrasted it to 'constructed' social organisation (Field, 2007: 26). For Coleman primordial social organisations are the cornerstone of social functioning and the depreciation of kin-ties has resulted in constructed social organisations, such as schools, playing a greater role in societal functioning (Field, 2007). Coleman's emphasis on the importance of such dense networks is problematic.

As Portes highlights, these networks '*tend to convey redundant information, while weaker ties can be sources of new knowledge and resources'* (Portes 1998:5). It would seem that, within Coleman's interpretation of social capital, viewing social capital as an unintentional by-product and by maintaining a nostalgic view of family Coleman misses the vital role of external ties. This is similar to criticisms that can be levelled against Bourdieu's emphasis on homophilous networks. However, Coleman's work widened the scope of social capital within the English speaking arenas of academia by illuminating the notion that all in society can benefit from social capital, not just those further up the social ladder.

PUTNAM: THE COMMUNITARIAN APPROACH

The approaches of Bourdieu and Coleman are network approaches; they view social capital in terms of the resources accessed via social networks (Moore *et al.,* 2006). There is no single network approach, for instance, Coleman focuses on social capital as a functional facilitator of individual and group action while Bourdieu focuses on the broader political ramifications (Moore *et al.,* 2006). Putnam's conceptualisation, on the other hand, is markedly different from both Bourdieu and Coleman. It can be argued that Putnam's communitarian approach to social capital is the conceptualisation which has had the greatest impact on the uses of ad understandings of social capital (Portes, 1998; DeFilippis, 2001; Baum & Ziersch, 2003). Putnam's social capital is characterised by civic participation, membership in voluntary associations, shared values, norms of reciprocity and trust in others. This approach has been labelled the communitarian approach.

While Coleman brought social capital into the mainstream Putnam popularised it. Putnam first used the term in *Making Democracy Work* (Putnam, Leonardi & Nanetti, 1993), a comparative study of Italy's regional governments. It was argued that governmental reforms of the 1970s were successful in Northern Italy but less successful in Southern Italy. This was because the North was supported by ample civic community, which was also the chief reason for economic prosperity in the North and paucity in the South. Putnam believed a proficient local administration and flourishing economy, results in an air of reciprocal co-operation, vital social networks, and civic participation (Putnam Leonardi & Nanetti, 1993). Putnam measured levels of civility by looking at newspaper readership, voting activity, membership in sports clubs and voluntary cultural associations and trust in political authority. Putnam thus defines social capital as '*features of social organizations, such as networks, norms, and trust that facilitate action and cooperation for mutual benefit'* (Putnam Leonardi & Nanetti, 1993: 35). As such this definition of social capital offered by Putnam is for all intents and purposes a definition of civil society. As DeFilippis comments, under Putnam, social capital is;

> *'…conflated with civil society, or more accurately, with a particular neo-Tocquevillean view of civil society. Thus, voluntary, nongovernment associations, based on trust, become the institutions through which social capital is generated … [social capital] becomes primarily a normatively good thing and is given credit for (a) promoting good, democratic government and (b) generating and sustaining economic growth and development'.* (2001:785)

This interpretation has parallels with Bourdieu in that social capital is a resource however the conceptualisations are fundamentally different. Bourdieu's version of social capital recognises the potential for exclusion and domination within social capital while for Putnam social capital is viewed as fundamentally a positive thing. Furthermore, within Bourdieu's theoretical approach social capital is but one aspect of a much wider understanding of the social.

Putnam later turned his attention to North America and published an article called *Bowling Alone: the Collapse and Revival of American Community* which later became a book, *Bowling Alone* (2000). Putnam argued that in the USA social capital was declining and had been doing so since the 1960s. Americans, according to Putnam, apply less time to voluntary organizations and casual gatherings which has had an adverse effect on society. Putnam stages his argument with the example of the decline in bowling leagues; *'bowling teams illustrate yet another vanishing form of social capital*' (Putnam, 2000: 205 [cited in Fine, Hallett & Sauder 2004]). This decline in social capital occurs alongside increased educational attainment, which usually leads to increased civic involvement. Putnam concludes that the criminal is television; Americans spend more time watching it then maintaining social connections.

This theory's ability to capture something of the zeitgeist within North America at the time enabled Putnam's civic partnership definition of social capital to take off, not just within academia but within the media (Portes 1998; Fine, Hallett & Sauder 2004). However, the problems become clear. As DeFilippis (2001) argues, Putnam's conceptualisation takes much from the work of Alexis De Tocqueville who believed that the voluntary associations could unite Americans and enlighten to the notion of

'nation'; a civil community beyond themselves that was independent of the state. Putnam seems to have been overcome by this idyllic representation of voluntary associations and as such believes social capital is '*closely related to what some have called 'civic virtue*'' (Putnam, 2000: 19); voluntary associations promote norms and trust which are positively remarkable in their ability to do good things for society. However, as Iglič argues, despite the theoretical expectations of the communitarian approach;

> *'…comparative studies have so far found only a weak statistical relationship between associational involvement and tolerance in Western democracies and a non-significant or even negative relationship in the case of Eastern and Central European countries… Associational involvement also has negative effects on political tolerance. Associations are social contexts within which processes of interpersonal influence and political mobilization take place. This results in the reinforcement of civic as well as uncivic orientations of associational members'* (2010: 717)

In short, Putnam's approach is potentially naïve, placing too much emphasis on the perceived benefits of voluntary associations.

Vertical & Horizontal Ties

While Putnam's conceptualisation of social capital is perhaps simplistic he does introduce some potentially useful ideas, for example, vertical and horizontal social ties in his analysis of Italian regions. The South was unsuccessful because of the role of '*vertical ties of dependence and exploitation'* (Putnam, 1993: 136), which prevented

the development of civic virtue, while the North prospered as social life tends to be based on '*horizontal ties of solidarity*'(*ibid*). Again this does speak to the Bourdieusian understanding of social capital in that it highlights the potential for social inequalities to be perpetuated by the status quo of the social hierarchy. Thus thinking with vertical and horizontal social ties is potentially useful. However, again it is perhaps a little simplistic as it does not account for the minor details inherent within inter-personal social interactions. Social life is never void of vertical ties it relies on vertical ties to some extent. Even Putnam's virtuous voluntary associations will have such ties and these ties can be useful; political voluntary associations, for example, can gain access to individuals further up the social hierarchy and thus voice their concerns. Ultimately, as DeFilippis argues,

> *'Putnam's understanding of the term, social capital becomes divorced from capital (in the literal, economic sense), stripped of power relations, and imbued with the assumption that social networks are win-win relationships and that individual gains, interests, and profits are synonymous with group gains, interests, and profits'.* (2001: 800)

OTHER ADDITIONS: BONDING, BRIDGING & LINKING SOCIAL CAPITAL

Gittell and Vidal (1998) introduced the bonding-bridging distinction. Woolcock (2001) further developed such distinctions providing definitions of bonding and bridging and a third type of social capital linking;

a) Bonding social capital – ties between similar people in comparable situations, for example family, close friends and possibly neighbours.
b) Bridging social capital – more distant ties, but still linked by similar people, for instance, weak friendships or work colleagues.
c) Linking social capital – ties between unlike people in differing circumstances. These ties can go outside of the community.

Putnam has utilised bonding and bridging social capital in later works, however, as Field remarks, Putnam '*does not really explore the logical conclusion, which is that different combinations will produce different outcomes'* (Field 2007: 42).

SUMMARY

The aim here has not been to suggest that either Putnam or Coleman are fundamentally wrong in their approaches but that these approaches are based on different assumptions than Bourdieu's. Furthermore, within the context of this thesis the approach offered by these theorists would be inappropriate. A core concern of thesis has been the subjective experiences and perceptions of stroke survivors. The Bourdieusian approach is not concerned just with social capital; social capital is a concept enmeshed within a particular approach which accounts for the embodied subject. This is ultimately why a Bourdieusian approach has been utilised and neither Putnam's approach, nor Coleman's approach, have been used to informed analysis.

APPENDIX 5.1: ETHICAL CONSIDERATIONS

Informed Consent: All potential participants were sent a letter informing them of what the study aimed to explore and what would be expected of those who agreed to participate. They were asked to sign a consent form prior to completing the survey. The information letter contained the author's contact details; office telephone number, University of Dundee e-mail address and department address. The participants were encouraged to contact the author if they had concerns or questions. Those who consented to be interviewed were contacted gain by letter to ensure they were still happy to proceed. Potential interviewees were provided with the choice of their home, an interview room within the University or a mutually convenient location of their choosing for the interview venue. At each interview, prior to recording, the purpose of the interview was reiterated and interviewees were offered the opportunity to ask questions if they wished. Each interview was audio-recorded as stated in the consent form. However, the author doubled checked that this was okay with each participant prior to beginning the recordings and informed the interviewees that the author would be the only individual to listen to the recordings and the written transcripts would be viewed by the author and the supervision team only.

Accessibility of Written Materials: As people with communication impairment were included within the sample the consent forms were made 'aphasia friendly'. This was to ensure people with communication impairment could engage with the study materials and provide informed consent.

Withdrawal: The potential participants were made aware that they could withdraw from the study at any time by contacting me on the contact details provided.

Furthermore, interviewees were informed that they did not have to answer questions which they were not comfortable answering. Interviewees were also informed of their right to withdraw from the interview at any point.

Anonymity and Confidentiality: The names and addresses of participants were only known to me and stored in a password protected computerised database. Each participant was given an identity number which was also assigned to the survey sent to the individual participants and the associated consent form. The consent forms and surveys were stored in a locked filing cabinet within a secure building. Each interviewee and individuals discussed within the interviews were provided with a pseudonym. Other identifiable information such as club membership and place names for example were altered within the transcripts in order to maintain anonymity.

Sensitive topics: The topics covered within the interviews were likely to be sensitive and had the potential to produce an emotional response. As such the author needed to be mindful of potentially sensitive topics. In practice where an interviewee appeared uncomfortable or unhappy probing was stopped and the interviewee asked whether they wished to continue in order to avoid harming the individual. Interviewees are also offered the opportunity to ask me questions at the end of the interview and the author would reiterate the aims of the study.

APPENDIX 5.2: ETHICAL APPROVAL

Tayside Committee on Medical Research Ethics A

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	08/S1401/84	**Issue number:**	1	**Date of issue:**	25 September 2008
Chief Investigator:	Miss Sian Russell				
Full title of study:	Reintegration after Stroke: Quality of Life, Employment and Social Capital				

This study was given a favourable ethical opinion by Tayside Committee on Medical Research Ethics A on 29 August 2008*. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.*

Principal Investigator	*Post*	*Research site*	*Site assessor*	*Date of favourable opinion for this site*	*Notes [1]*
Miss Sian Russell	Research Student	NHS Tayside	Tayside Committee on Medical Research Ethics A	18/09/2008	
Miss Sian Russell	Research Student	NHS Fife Victoria Hospital, Hayfield Road, Kirkcaldy, Fife KY2 5AH	Fife and Forth Valley REC	18/09/2008	

Approved by the Chair on behalf of the REC:

..... (Signature of Chair/Co-ordinator)

(delete as applicable)

..... (Name)

APPENDIX 5.3: INFORMATION SHEET

Information Sheet

My name is **Siân Russell**.
I am a **PhD** student at the **University of Dundee**
I am doing a study for my course.
I would **like you to help**.

I need to make sure **you understand what the study is about**.
Feel free to:

- **Contact me** on the details provided at the end of this document
- talk to friends and family

What is the study about?

The study is called "**Reintegration after Stroke**"

Reintegration = **taking part in life again**. This could be:

- paid employment
- voluntary work
- meeting friends and family

I want to increase understanding about:

- **life after a stroke**
- **long-term support needs**

The study will look at issues, including:

- Experiences of **care**

- **Social life**

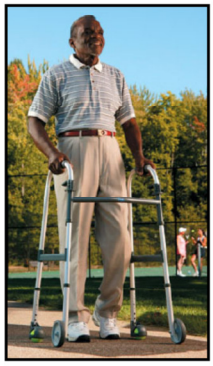
- **Work**

- **Leisure** activities

- **Money**

- **Your background**

- **Physical ability**



These topics will **help me understand how stroke survivors manage their lives**.

Results will be reported to the **NHS** and **research community.**

How have I been invited to take part?

Ninewells Hospital has a **Stroke Studies Centre**.
The Centre works closely with the Acute Stroke Unit at Ninewells.
The centre has a **list of patients** who have had a **stroke in Tayside.**

The list is **private**.
It can only be used for:

- **medical reasons**
- **studies approved by an NHS Research Ethics Committee**

Tayside Committee on Medical Research Ethics has agreed that I can use the list.

You were chosen from this list.
I did <u>not</u> look at medical records.

Do I have to take part?

No
Taking part is **<u>your</u> choice**.
You can **<u>stop</u> at any time**.
This will **<u>not</u> affect your care**.

Please **sign the consent form enclosed** if,

- you **agree** to take part
- you **understand what the study is about**

If you have any **further questions** you can **contact me**.
Contact details are at the end of this document.

What happens during the study?

The study has **two stages**.

- a **survey**

- an audio-recorded **interview**

You may want **Help** to fill out the survey.

If you need help you could **ask the following people**

- A relative
- A friend
- A speech and language therapist or another healthcare worker

If you have help **please ensure the answers provided are yours and not those of the person helping you.**

The survey could take **between 15 minutes and 1 hour** to complete**. Please -**

- fill it out at **your own pace**
- **take breaks** if you need to

Some people will be asked to give more information in an **interview**. **Most people** will only need to do the survey.
The interviews will,

- be **audio-recorded**

- be with me
- cover **similar topics to the survey**
- be on a more **individual and detailed** level
- take around **1 hour**
- take place in the **University of Dundee or at home as <u>you</u> wish**

The information gathered will be **kept private**.
All data gathered will be studied.

What happens after the study?

Once the **study ends** those who took part will be **notified**. **Findings will be reported** to NHS Tayside, voluntary groups, academic conferences and within journals.
Those who took part can **request a summary report** from me.

Once the results have been reported all personal data will be destroyed.
Remaining data will be archived for no less than 10 years. **This archive will be secure.**

How Do I Take Part

To take part,

- read **this information sheet**
- fill out and **sign the consent form** (enclosed)
- you will be required to complete out the **survey** sent to you in the post
- give a **honest account of your experiences**

For **most** of you this will be **all you need to do.**

Some of you will also be asked to take part in an **interview**.

If you take part in an interview please,

- understand the interview will be **audio-recorded**
- give an **honest account of your experiences**

Are there any risks?

Some topics **could be sensitive**.

However, all personal data will be **kept private**.

What are the benefits of taking part?

The study will help my team **understand life after stroke.**

This will help **improve care** for **people who have had a stroke**

What if I have more questions?

If you have **questions** about the study please **contact me, Sian Russell,** for more information on the study.

Siân Russell

School of Nursing & Midwifery

The University of Dundee

11 Airlie Place

Dundee,

DD1 4HJ

E-mail: s.z.russell@dundee.ac.uk

Tel: 01382 388534 Ext. 7788555

Thank you for reading this information sheet

APPENDIX 5.4: CONSENT FORM

CONSENT FORM – Reintegration After Stroke Study

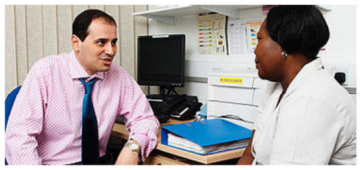
Your information will be kept **private**.

Please tick ☑ **Yes**  or **No**  to the following.

Do you understand …

… the **information sheet** provided Yes ☐ No ☐

… your GP has been **informed** of this study Yes ☐ No ☐



… taking part is **your choice** Yes ☐ No ☐

Do you understand ...

... you can **stop at any time** Yes ☐ No ☐

... this would **not affect your medical care** Yes ☐ No ☐

... only the study team will see **data collected** Yes ☐ No ☐

... your **home address** has been taken from **computer records** held by the Health Board Yes ☐ No ☐

... **when the study ends** you will be told Yes ☐ No ☐

... **interviews** will be **audio-taped** Yes ☐ No ☐

Finally...

... do you **agree to take part** in the study? Yes ☐ No ☐

Please sign below

Your signature_____

Your name in BLOCK LETTERS_____

Date_____

If you **had help,** please have the **person who helped print and sign** their name **in the box below**.

Helper's signature_____

Helper's name in BLOCK LETTERS_____

Date_____

Please send this back in the **enclosed** stamped and addressed **envelope provided** by the **21st August 2009**.

Thank you

APPENDIX 5.5: SURVEY

LIFE AFTER STROKE

NHS SCOTLAND

A study funded By the Chief Scientist Office (CSO)

CHIEF SCIENTIST OFFICE

About this Survey

This survey explores the lives of **stroke survivors in Tayside**.

By taking part in this survey you will **help increase understanding** about

- **life after a stroke**
- long-term **support needs of stroke survivors**

This study has been **approved** by **Tayside Committee on Medical Research Ethics.**

This study is being conducted under the guidance of **The University of Dundee.**

As required by the National Research Ethics Service of the NHS **all your answers and all personal details to be kept private.**

Before you begin the survey -

Please **make sure** you have **read the information sheet** and **signed** the **consent form**

Please **send this survey back** in the addressed and stamped **envelope provided**

Please take time to **carefully read the instructions on the next page**

How to fill out this survey

You may want **Help** to fill out the survey

If you need help you could **ask the following people**

- A relative
- A friend
- A speech and language therapist or another healthcare worker

If you have help please ensure the answers provided are yours and not those of the person helping you.

Avoid Tiring Yourself Out!

fill it out **at your own pace** **AND** **take breaks** if you need to

The Survey has **Four Sections**

- **About you** – questions on age, gender, experience of care, employment, income and finances, education, interests and social life.
- **Stroke Impact Scale** - questions about your **physical functioning**.
- **Burden of Stroke Scale** - questions on **difficulties** you may have as a result of **your stroke**.
- **Final checks** - asks whether you are happy to be **interviewed** and whether you had **help** filling out this survey.

For **most** questions you only need to **cross a box** as pictured below.

1. What **age band you are in**?

45-54 ☐ 55-64 ☐ 65-74 ☒ 75-84 ☐ 85 + ☐

For **some** questions you need to **write in** your answer.

Read the Questions Carefully

About You - Background Questions

1. What **age** band are you in?

☐ 45 - 54 ☐ 55 - 64 ☐ 65 - 74 ☐ 75 - 84 ☐ 85 +

2. What is your **sex?**

☐ Male ☐ Female

3. What is your **ethnic origin?**

☐ White British ☐ Dual heritage ☐ Asian

☐ Black ☐ Chinese ☐ Other

4. What is your **current marital status?** Please select **one** only.

☐ Long-term committed relationship (living apart) ☐ Separated

☐ Long-term committed relationship (living together) ☐ Single

☐ Married ☐ Divorced

☐ Widowed

5. Do you have **children**?

☐ Yes - answer **questions 5a to 5c <u>before</u>** moving on to **question 6**

☐ No - please move on to **question 6**

5a. How many children do you have?

.....

5b. Are any of your children **dependents**?

☐ Yes ☐ No

5c. Do you have any **grandchildren**?

☐ Yes ☐ No

6. What is your **religious affiliation?**

☐ None ☐ Church of Scotland

☐ Roman Catholicism ☐ Other Christian

☐ Buddhism ☐ Hinduism

☐ Judaism ☐ Islam

☐ Sikhism ☐ Other

7. How long have you **lived** in **Tayside** or **Fife**?

.....

Feel Free to **take a break**

Remember to **ask for help** if you need it

About You - Experience of care

8. Below is a **statement about stroke**.

Please select the response which is **most suited to you.**

	Strongly Agree	**Agree**	**Neither** Agree nor Disagree	**Disagree**	**Strongly Disagree**
I knew what a stroke was **before** I had one	☐	☐	☐	☐	☐

9. Below are a series of statements about **the care** you received **at the <u>time</u> of your stroke.**

Please select the response which is **most suited to you**.

	 **Strongly Agree**	 **Agree**	 **Neither** Agree nor Disagree	 **Disagree**	 **Strongly Disagree**
I had **confidence** in the **<u>care</u>** I received	☐	☐	☐	☐	☐
Staff kept me well **informed** of my **condition**	☐	☐	☐	☐	☐
Staff **listened** to my **questions**	☐	☐	☐	☐	☐
Staff **answered** my **questions**	☐	☐	☐	☐	☐
When my **treatment** was discussed, staff **talked directly to <u>me</u>**	☐	☐	☐	☐	☐

10. Below are a series of statements about **the <u>care</u> you have received <u>since</u> your stroke.**

Please select the response which is **most suited to you**.

	 **Strongly Agree**	 **Agree**	 **Neither** Agree nor Disagree	 **Disagree**	 **Strongly Disagree**
I **know how** to **manage my health** following my stroke.	☐	☐	☐	☐	☐
I am **happy** with **the care** I receive.	☐	☐	☐	☐	☐

About You - Money

11. Please select the income band closest to your **current annual household income**.

☐ Below £10,000 a year	☐ 10, 000	☐ 11, 000 – 15, 000
☐ 16, 000 – 20, 000	☐ 21, 000 – 25, 000	☐ 26, 000 – 30, 000
☐ 31, 000 – 35, 000	☐ 36, 000 – 40, 000	☐ 41, 000 and over

I2. If you are living in your own home, do you **own or rent** it?

☐ I do **not live** in my **own home**	☐ **Own** out right
☐ **Mortgage**	☐ **Renting**

☐ Other, please specify

.....

13. Below are two statements on **financial circumstances**.

Please select the response which is **most suited to you**.

	Strongly Agree	**Agree**	**Neither** Agree nor Disagree	**Disagree**	**Strongly Disagree**
My finances **meet my needs**	☐	☐	☐	☐	☐
The current financial climate has **not affected** my finances.	☐	☐	☐	☐	☐

About You - Education

14. Please select **your highest educational attainment**.

☐ Less than high (secondary) school ☐ High (secondary) school

☐ Community Collage ☐ University (undergraduate)

☐ University (Postgraduate)

☐ Other – please specify.....

15. Please select the **highest educational attainment of your <u>father</u>**, if known.

☐ Unknown ☐ Less than high (secondary) school

☐ High (secondary) school ☐ Some further education

☐ University (Undergraduate) ☐ University (Postgraduate)

☐ Other – please specify.....

16. Please select the **highest educational attainment of your <u>mother</u>**, if known.

☐ Unknown ☐ Less than high (secondary) school

☐ High (secondary) school ☐ Some further education

☐ University (Undergraduate) ☐ University (Postgraduate)

☐ Other – please specify.....

17. Please select the **type of schooling you** have had.

☐ Private schooling ☐ State schooling

☐ Home schooling ☐ Other – please specify

.....

Feel Free to **take a break**

Remember to **ask for help** if you need it

PLEASE READ THE FOLLOWING QUESTIONS CAREFULLY

About You - Employment

18. Before your stroke were you **employed**?

☐ Yes - please answer **questions 19a to 19b** before question 13

☐ No - please answer **question 19c** before question 13

19a. Were you in a **full or part** time position?

☐ Full time ☐ Part time

19b. Below is a list of **occupational** categories.

Please select the type of **job you held before your stroke**.

☐ Self-employed professional

☐ Professional

☐ High level management

☐ Semi - professional

☐ Technician

☐ Middle manager

☐ Supervisor

☐ Foreman / woman

☐ Skilled clerk / sales / service

☐ Skilled craftsman / woman

☐ Farmer

☐ Semi - skilled clerk / sales / service

☐ Semi - skilled manual

☐ Unskilled clerk / scales / service

☐ Unskilled manual

19c. Why were you **unemployed before your stroke**?

Please select **one** of the following options

- ☐ Retired
- ☐ Physically unwell
- ☐ Mentally unwell
- ☐ Housewife / husband
- ☐ Carer
- ☐ Trouble finding work
- ☐ Recently made redundant

20. Before your stroke, did you have any **prolonged** periods of **unemployment**? (4 months +)

- ☐ Yes - please answer **question 21 before question 22**
- ☐ No - please move on to **question 22**.

21. Why were you **unemployed** for a **prolonged period**?

Please select **one** of the following options

- ☐ Physical illness
- ☐ Mental illness
- ☐ Housewife / Husband
- ☐ Carer
- ☐ Trouble finding work

22. Are you **currently employed**?

- ☐ Yes - please answer **question 23a before question 24**
- ☐ No - please answer **question 23b before question 24**

23a. Below is a list of **occupational** categories.

Please select the occupational category of your **current job**.

- ☐ Self-employed professional
- ☐ Professional
- ☐ High level management
- ☐ Semi - professional
- ☐ Technician
- ☐ Middle manager
- ☐ Supervisor
- ☐ Foreman / woman
- ☐ Skilled clerk / sales / service
- ☐ Skilled craftsman / woman
- ☐ Farmer
- ☐ Semi - skilled clerk / sales / service
- ☐ Semi - skilled manual
- ☐ Unskilled clerk / scales / service
- ☐ Unskilled manual

23b. Why are you **currently unemployed**?

Please select **one** of the following options

☐ Retired ☐ Physically unwell

☐ Mentally unwell ☐ Housewife / husband

☐ Carer ☐ Trouble finding work

☐ Recently made redundant

24. Do you work as an **unpaid volunteer**?

☐ Yes ☐ No

Feel Free to **take a break**

Remember to **ask for help** if you need it

Interests

25. If any which type of **newspaper** do you read **regularly**?

☐ I **do** **not** read any newspapers regularly

☐ Broadsheet - **for example** "The Guardian" "The Times" "The Independent"

☐ Tabloid - **for example** "The Sun" "News of the World" "The Mirror"

☐ Local news paper – **for example** "The Courier"

26. If at all, which of the following mediums do you use to **follow the news**? Please select **all that apply**.

☐ I do **not** follow the news ☐ The **Internet**

☐ **Television** ☐ **Newspaper**

☐ **Radio**

27. If there were an **election tomorrow**, how likely is it that you would **want to vote**?

☐ **Very Likely** ☐ **Likely**

☐ **Very Unlikely** ☐ **Unlikely** ☐ **Unsure**

PLEASE READ THE FOLLOWING QUESTIONS CAREFULLY

28. Below is a list of **leisure activities**. Do you consider any to be **of <u>interest</u>** to you?

Please select **up to <u>five</u>**

☐ Foreign travel	☐ Art	☐ Classical music
☐ Reading	☐ Football	☐ Rugby
☐ Art house films	☐ Blockbuster movies	☐ Theatre
☐ Gardening	☐ Walking	☐ Swimming
☐ Cycling	☐ Popular music	☐ Golf

☐ Other, please specify.....

29. **<u>Before</u> your stroke** did you **<u>actively</u> pursue** any of the following **leisure activities**?

<u>Please select **up to five**</u>.

☐ Foreign travel	☐ Art	☐ Classical music
☐ Reading	☐ Football	☐ Rugby
☐ Art house films	☐ Blockbuster movies	☐ Theatre
☐ Gardening	☐ Walking	☐ Swimming
☐ Cycling	☐ Popular music	☐ Golf

☐ Other, please specify.....

30. **<u>Since</u> your stroke** do you **<u>still</u> <u>actively</u> pursue** any of the following **leisure activities**?

<u>Please select **up to five**</u>

☐ Foreign travel	☐ Art	☐ Classical music
☐ Reading	☐ Football	☐ Rugby
☐ Art house films	☐ Blockbuster movies	☐ Theatre
☐ Gardening	☐ Walking	☐ Swimming
☐ Cycling	☐ Popular music	☐ Golf

☐ Other, please specify.....

31. Do you <u>now</u> actively pursue any leisure activities which you **did <u>not</u> pursue before your stroke**?

<u>Please select **up to five**</u>

☐ Foreign travel	☐ Art	☐ Classical music
☐ Reading	☐ Football	☐ Rugby
☐ Art house films	☐ Blockbuster movies	☐ Theatre
☐ Gardening	☐ Walking	☐ Swimming
☐ Cycling	☐ Popular music	☐ Golf

☐ Other, please specify.....

Feel Free to **take a break**

Remember to **ask for help** if you need it

About you - Social Life

32. From the list below please select **your current** living arrangements

Please select **one only**

☐ I live **alone**

☐ I live with my **partner** only

☐ I live with **family**

☐ I live with **others** to whom I am **not related**

☐ I live in **supported accommodation** / sheltered housing / care-home

33. Do you have **family** who **live close-by**?

☐ Yes –please answer **question 34 before question 35**

☐ No – please move on to **question 35**

34. Please specify **how close-by** this family member / these family members live.

☐ Under 1 mile	☐ 1 mile	☐ 2 -5 miles
☐ 6 -10 miles	☐ 11-15 miles	☐ 16 miles and over

35. How often do you **meet socially with ...**

	Regularly	Occasionally	Never	N / A
Family members who you do **not live with**	☐	☐	☐	☐
Neighbours	☐	☐	☐	☐
Current or former **work colleagues**	☐	☐	☐	☐
Friends who are **not** neighbours or work colleagues	☐	☐	☐	☐

36. How often do you **talk with** the following people on the **phone**, by **e-mail** or **social networking sites** (**for example** Skype, MSN Messenger, Facebook)

	Regularly	Occasionally	Never	N / A
Family members who you do **not live with**	☐	☐	☐	☐
Neighbours	☐	☐	☐	☐
Current or former **work colleagues**	☐	☐	☐	☐
Friends who are **not** neighbours or work colleagues	☐	☐	☐	☐

37. In the past **12 months**, have you been an **active member** of a **stroke club** or group?

☐ Yes ☐ No

38. In the past **12 months**, have you been an **active member** of any **other** local club or group?

This could be a sports, reading, art, or drama club for example.

☐ Yes ☐ No

39. Below is a series of comments about **social relationships**.

Please select the response which is **most suited to you**.

	 **Strongly Agree**	 **Agree**	 **Neither** Agree nor Disagree	 **Disagree**	 **Strongly Disagree**
I **never** feel **lonely**	☐	☐	☐	☐	☐
I **never** feel **excluded**	☐	☐	☐	☐	☐
My **social life** has become **<u>less</u> active since my stroke**	☐	☐	☐	☐	☐
I feel that I can **trust most people**	☐	☐	☐	☐	☐
I have **many social ties** to call on	☐	☐	☐	☐	☐
Friends do **<u>not</u>** treat me **any differently since my stroke**	☐	☐	☐	☐	☐
Family do **<u>not</u>** treat me any **differently since my stroke**	☐	☐	☐	☐	☐

Stroke Impact Scale

In the past two weeks, how difficult was it to…

	 Not difficult at all	 A little difficult	 Some-what difficult	 Very difficult	 Could not do at all
Dress the **top part** of your **body**?	☐	☐	☐	☐	☐
Bathe yourself?	☐	☐	☐	☐	☐
Get to the **toilet on time**?	☐	☐	☐	☐	☐
Control your bladder (not have an accident)?	☐	☐	☐	☐	☐
Control your bowels (not have an accident)?	☐	☐	☐	☐	☐
Stand without losing **balance**?	☐	☐	☐	☐	☐
Go **shopping**?	☐	☐	☐	☐	☐
Do heavy **household chores** (vacuum, laundry or gardening)?	☐	☐	☐	☐	☐
Stay **sitting** without losing your **balance**?	☐	☐	☐	☐	☐
Walk without losing your **balance**?	☐	☐	☐	☐	☐
Move from a **bed** to a **chair**?	☐	☐	☐	☐	☐
Walk fast?	☐	☐	☐	☐	☐
Climb **one flight of stairs**?	☐	☐	☐	☐	☐
Walk one block (**street**)?	☐	☐	☐	☐	☐
Get **in and out of a car**?	☐	☐	☐	☐	☐
Carry heavy objects (bag of groceries) with your **affected hand**?	☐	☐	☐	☐	☐

Feel Free to **take a break**

Remember to **ask for help** if you need it

Burden of Stroke Scale

This survey is about **specific difficulties you may have** as a result of **your stroke**, and how they have **affected your life**.

When answering questions, please keep in mind that "**difficulty**" **can mean**:

- **increased effort,**

- **discomfort or pain**,

- **slowness, or**

- **changes in the way that you do the activity**.

When answering questions about how **stroke-related difficulties** have **affected your life**, please keep in mind that there are **no right or wrong answers**, but it is very important for you to indicate **what you think and feel** about your situation.

Mobility: The first set of questions is about difficulties that you may have moving around inside or outside of your home.

Because of your stroke, how <u>difficult</u> is it for you to...

	 Not at all	 A little	 moderately	 very	 Cannot do	NA
Maintain your **balance**?	☐	☐	☐	☐	☐	☐
Walk one flight of **stairs**?	☐	☐	☐	☐	☐	☐
Stand-up from a resting position?	☐	☐	☐	☐	☐	☐
Kneel down or bend over?	☐	☐	☐	☐	☐	☐
Get to where you want as **quickly** as you would like?	☐	☐	☐	☐	☐	☐

If you marked "Not at all" or "NA" for **<u>all</u>** of the questions above, mark "NA" for the next three questions. Otherwise, please answer the following questions.

	 Never	 Rarely	 Sometimes	 Often	 Always	NA
How often do **difficulties moving** around cause you to feel **anxious unhappy** or **frustrated**?	☐	☐	☐	☐	☐	☐
How much do **difficulties moving** around cause you to feel **dissatisfied** with **yourself** and **your life**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA
How much do **difficulties moving** around **prevent** you from doing the **things** in life that are **important to you**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA

Self care: The next set of questions asks about difficulties you may have in taking care of your personal every day needs.

Because of your stroke, how <u>difficult</u> is it for you to...

	 Not at all	 A little	 moderately	 very	 Cannot do	NA
Dress yourself?	☐	☐	☐	☐	☐	☐
Bathe yourself?	☐	☐	☐	☐	☐	☐
Do **light** household **chores**?	☐	☐	☐	☐	☐	☐
Prepare meals for yourself or your family?	☐	☐	☐	☐	☐	☐
Do **everyday activities** as **quickly** as you would like?	☐	☐	☐	☐	☐	☐

If you marked "Not at all" or "NA" for **<u>all</u>** of the questions above, mark "NA" for the next three questions. Otherwise, please answer the following questions.

	 Never	 Rarely	 Sometimes	 Often	 Always	NA
How often do **difficulties** in taking care of **your personal needs** cause you to feel **anxious unhappy** or **frustrated**?	☐	☐	☐	☐	☐	☐
How often do **difficulties** in taking care of **your personal needs** cause you to feel **dissatisfied** with **yourself** and **your life**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA
How often do **difficulties** in taking care of **your personal needs prevent** you from doing the **things** in life that are **important to you**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA

Communication: The next set of questions asks about difficulties you may have communicating

Because of your stroke, how <u>difficult</u> is it for you to...

	 Not at all	 A little	 moderately	 very	 Cannot do	NA
Talk?	☐	☐	☐	☐	☐	☐
Understand what people **say** to you?	☐	☐	☐	☐	☐	☐
Understand what you **read**?	☐	☐	☐	☐	☐	☐
Write a letter?	☐	☐	☐	☐	☐	☐
Talk with a **group** of people?	☐	☐	☐	☐	☐	☐
Be understood by others?	☐	☐	☐	☐	☐	☐
Find the words you want to say?	☐	☐	☐	☐	☐	☐

If you marked "Not at all" or "NA" for **<u>all</u>** of the questions above, mark "NA" for the next three questions. Otherwise, please answer the following questions.

	 Never	 Rarely	 Sometimes	 Often	 Always	NA
How often do **difficulties communicating** cause you to feel **anxious unhappy** or **frustrated**?	☐	☐	☐	☐	☐	☐
How often do difficulties communicating cause you to feel dissatisfied with yourself and your life?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA
How often do difficulties communicating prevent you from doing the things in life that are important to you?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA

Cognition: The next set of questions asks about difficulties you may have thinking an remembering

Because of your stroke, how <u>difficult</u> is it for you to...

	 Not at all	 A little	 moderately	 very	 Cannot do	NA
Concentrate?	☐	☐	☐	☐	☐	☐
Solve a problem?	☐	☐	☐	☐	☐	☐
Remember to do your everyday **tasks**?	☐	☐	☐	☐	☐	☐
Learn new things?	☐	☐	☐	☐	☐	☐
Remember what people **say**?	☐	☐	☐	☐	☐	☐

If you marked "Not at all" or "NA" for **<u>all</u>** of the questions above, mark "NA" for the next three questions. Otherwise, please answer the following questions

	 Never	 Rarely	 Sometimes	 Often	 Always	NA
How often do **difficulties thinking** and **remembering** cause you to feel **anxious unhappy** or **frustrated**?	☐	☐	☐	☐	☐	☐
How often do **difficulties thinking** and **remembering** cause you to feel **dissatisfied** with **yourself** and **your life**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA
How often do **difficulties thinking** and **remembering prevent** you from doing the **things** in life that are **important to you**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA

Swallowing: The next set of questions asks about difficulties you may have swallowing

Because of your stroke, how <u>difficult</u> is it for you to...

	 Not at all	 A little	 moderately	 very	 Cannot do	NA
Chew food **without loosing some** from your mouth?	☐	☐	☐	☐	☐	☐
Swallow <u>solid</u> foods?	☐	☐	☐	☐	☐	☐
Swallow <u>liquids</u>?	☐	☐	☐	☐	☐	☐

If you marked "Not at all" or "NA" for **<u>all</u>** of the questions above, mark "NA" for the next three questions. Otherwise, please answer the following questions

	 Never	 Rarely	 Sometimes	 Often	 Always	NA
How often do **difficulties chewing** and **swallowing** your food cause you to feel **anxious unhappy** or **frustrated**?	☐	☐	☐	☐	☐	☐
How often do **difficulties chewing** and **swallowing** your food cause you to feel **dissatisfied** with **yourself** and **your life**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA
How often do **difficulties chewing** and **swallowing** your food **prevent** you from doing the **things** in life that are **important** to you?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA

Social Relationships: The next set of questions asks about difficulties you may have in social situations and relationships

Because of your stroke, how <u>difficult</u> is it for you to...

	 Not at all	 A little	 moderately	 very	 Cannot do	NA
Enjoy leisure activities with **friends** and **relatives**?	☐	☐	☐	☐	☐	☐
Keep **old friendships** going?	☐	☐	☐	☐	☐	☐
Maintain your role as a friend or family member?	☐	☐	☐	☐	☐	☐
Interact with people you're **meeting** for the **first time**?	☐	☐	☐	☐	☐	☐
Interact with **friends** and **family** members?	☐	☐	☐	☐	☐	☐

If you marked "Not at all" or "NA" for **<u>all</u>** of the questions above, mark "NA" for the next three questions. Otherwise, please answer the following questions

	 Never	 Rarely	 Sometimes	 Often	 Always	NA
How often do difficulties in **social situations** or **relationships** cause you to feel **anxious unhappy** or **frustrated**?	☐	☐	☐	☐	☐	☐
How often do difficulties in **social situations** or **relationships** cause you to feel **dissatisfied** with **yourself** and **your life**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA
How often do difficulties in **social situations** or **relationships prevent** you from doing the **things** in life that are **important to you**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA

Energy and Sleep: The next set of questions asks about difficulties you may have with energy and sleep

Because of your stroke, how <u>difficult</u> is it for you to...

	 Not at all	 A little	 moderately	 very	 Cannot do	NA
Get **enough sleep**?	☐	☐	☐	☐	☐	☐
Have **enough energy** to take care of your **personal needs**?	☐	☐	☐	☐	☐	☐
Have **enough energy** to **think clearly**?	☐	☐	☐	☐	☐	☐
Stay awake throughout **the day**?	☐	☐	☐	☐	☐	☐

If you marked "Not at all" or "NA" for **<u>all</u>** of the questions above, mark "NA" for the next three questions. Otherwise, please answer the following questions

	 Never	 Rarely	 Sometimes	 Often	 Always	NA
How often do difficulties with **energy** and **sleep** cause you to feel **anxious unhappy** or **frustrated**?	☐	☐	☐	☐	☐	☐
How often do difficulties with **energy** and **sleep** cause you to feel **dissatisfied** with **yourself** and your **life**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA
How often do difficulties with **energy** and **sleep prevent** you from doing the **things** in life that are **important to you**?	☐ Not at all	☐ A little	☐ Some	☐ A lot	☐ completely	☐ NA

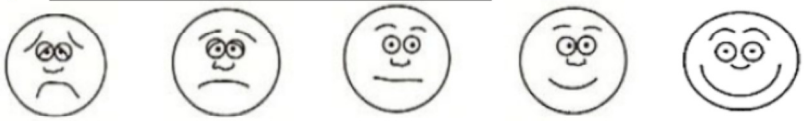
Positive and Negative Feelings: The final set of questions asks about your feelings and emotions. Please keep in mind that there are no right or wrong answers, but it is very important for you to indicate what you think and feel about your situation.

Since your stroke, how often do you feel...

	Never	Rarely	Sometimes	Often	Always	NA
Lonely?	☐	☐	☐	☐	☐	☐
Anxious?	☐	☐	☐	☐	☐	☐
Angry?	☐	☐	☐	☐	☐	☐
Sad?	☐	☐	☐	☐	☐	☐

	Not at all	A little	Some	A lot	completely	NA
How often do your **feelings** and **emotions prevent** you from doing the **things** in life that are **important to you**?	☐	☐	☐	☐	☐	☐

Since your stroke, how often do you feel...



	Never	Rarely	Sometimes	Often	Always	NA
Confident?	☐	☐	☐	☐	☐	☐
Happy?	☐	☐	☐	☐	☐	☐
Calm?	☐	☐	☐	☐	☐	☐
Optimistic about the **future**?	☐	☐	☐	☐	☐	☐

And Finally

As outlined in the **information sheet**, some, some of you may be asked to take part in a **face-to-face interview**. Interviews will;

- expand upon the issues in this survey
- take around an **hour**
- be **audio-recorded**
- be conducted at the University of Dundee or in your home if you wish

Would you be willing to **take part in an interview**?

Yes ☐ No ☐

Did you receive help to fill out this survey?

Yes ☐ No ☐

Please make sure you have **read the information sheet**

Please check through the survey to ensure you have **answered all the questions**

Please send this survey back in the **addressed and stamped envelope provided**

Feel free to write in **any comments** in the space provided.

.....

.....

.....

.....

.....

.....

.....

.....

Thank you very much for your time and honesty

APPENDIX 5.6: CRONBACH'S α

The results of the Cronbach's α for the rudimentary and validated scales are presented below.

Table A5.1: Cronbach's α results

Scale	**Cronbach's α**
Rudimentary Scales	
Social Capital	0.717
Sense of Inclusion	0.773
Cultural Capital	0.828
Validated Scales	
Burden of Stroke Scale	0.895
Stroke Impact Scale-16	0.867

From the table above it is clear that all the scales have achieved a Cronbach's α of 0.7 or above. The Social Capital Scale and Sense of inclusion scale achieved an acceptable Cronbach's α of 0.7. The Cultural Capital Scale achieved a preferred Cronbach's α of 0.8. Therefore each scale can be said to have internal consistency. Unsurprisingly the validated scales both achieved Cronbach's α of 0.8.

APPENDIX 5.7: PERSONALISED INTERVIEW TOPIC GUIDE

Interview Topic Guide – (Interview 16)

Protocol for Researcher:

☐ Thank interviewee for agreeing to take part in this research project
☐ Reiterate the purpose of the research, ensuring that interviewee is fully aware of the reasons for involvement
☐ Explain to interviewee that the interview is voluntary, that they can pull out at any time and that they should feel comfortable to inform the interviewer if any topics or questions need further clarification or causes offence
☐ The interview will take no longer than one hour and will be audio recorded for transcription purposes
☐ Interview transcripts will be anonymous and the original recording deleted. Only the researcher will know the identity of the interviewee for each audio recording and transcription.
☐ Present interview confidentiality / consent sheet x 2: one copy to be kept by the interviewer (stored in a locked cabinet) and the other kept by the interviewee for their own peace of mind
☐ Ask the interviewee whether they have any questions which they would like to discuss before we begin
☐ Ensure that the interviewee is comfortable
☐ Test audio and begin

- **Impairments: Mobility (no aphasia)**

Data to mine:

- **Family based social capital appears to be high / inclusion low**
- **Social Relationships sub-scale in BOSS scores suggests some difficulty maintaining 'role' and meeting new people.**
- **Drop in leisure activities (3 to 1)**

Questions

Topic – Having the stroke and coming out of hospital

☐ Ask the interviewee to describe the experience of having the stroke in her or his own words.

☐ Ask her or him to describe how s/he felt on being told s/he had had a stroke.

☐ Ask the interviewee to describe in her/his own words the experience of coming out of hospital.

PROBE: When, age, in what circumstances / where (home, work or exceptional) did the stroke occur?
PROBE: How long was she in hospital?
PROBE: Family and friends' reactions.
PROBE: Did the patient and family members get access to the information they needed?
PROBE: What kind of help did she receive?

Topic – Social Networks and relations

INTRODUCE NETWORK BOARD: Ask interviewee to think about the people they know and place them on the network board

('Important' people to be placed in the central section)

☐ Ask interviewee to think about who is important to them and to place them on the network board
PROBE: Interviewee is married, ask about husband
How did he react?
Has there been a change in roles undertaken?
PROBE: Interviewee has family within 5 miles of address
How many relatives live in the local area?
Do they visit often?
What kinds of support do they offer?
PROBE: Interviewee has LOW sense of inclusion
Has she been able to get involved in family occasions as much as she would like?
Does she now spend more time with the family than she did prior to the stroke?
Do family members alter leisure activities to accommodate and include them?

☐ Ask the interviewee to talk about the people they socialise with regularly.
PROBE: Interviewee meets with friends 'occasionally'
Who are these friends? / How do they know each other and for how long?

Has the stroke changed how often she meets friends?

PROBE: In what circumstances does she meet with people socially?

(e.g. - going for lunch, visiting friends' homes, meeting at the pub, going to the movies, pursuing hobbies).

Has the stroke changed these circumstances?

PROBE: Who are the people she socialises with the most?

Family, old friends, neighbours, people she has met since having the stroke?

PROBE: Are there people she no longer socialises with?

PROBE: She is a member of a club

What is the nature of the club?

Did she do this before the stroke?

Is she as involved in the club as much as before the stroke?

How have people as the club reacted to the stroke?

How important is going to the club?

PROBE: She is not a member of a stroke club

Has she heard of a stroke club?

If yes, why not go?

If no, would she be interested?

What would she want from such a club?

☐ Interviewee indicated meeting new people was problematic in BOSS scale

PROBE: Ask her to explain why

☐ Interviewee indicated fulfilling her role with family / friends was problematic in the BOSS scale.

PROBE: Ask her to explain why

Topic– Employment/finances

☐ **Interviewee was retired prior to stroke**

PROBE: if not mentioned earlier ask about former work colleagues

Still in contact?

How often do they meet?

PROBE: How important was their job – what kinds of skills involved (has she lost certain work related skills?)

PROBE: Ask what her plans were for retirement

Have plans changed due to her stroke?

If so, how does this make her feel?

How does she think her husband feels?

☐ **Interviewee does not volunteer**

PROBE: Ask whether this is something she's thought about. If yes, why does she not – is this related to impairments

☐ **If not mentioned already, ask whether the stroke has impacted on finances**

PROBE: In what way?

PROBE: how does this make her feel?

Topic – Hobbies / Leisure

☐ Interviewee indicated she had 3 hobbies before her stroke and now only has 1
PROBE: How important is – reading?
PROBE: How important was – bingo?
PROBE: How important was – knitting?
PROBE: How important was – walking?
PROBE: Have there been any other lost activities?
Going out / housework / looking after grandchildren?
PROBE: Has this impacted on socialising?
PROBE: How does the loss of activities make her feel?
PROBE: Has she tried to replace activities?

Topic – The self

☐ Ask the interviewee to talk about who she is and how she views herself.
PROBE: Has changed due to the stroke?
Personality, bubbly and out going or quite and restrained, physical appearance, mobility.
☐ Knowing what you know now is there anything she would do differently?
☐ Ask her to openly discuss any other experiences or issues which are important to her

Final issues

☐ **Ask the interviewee if she has any questions for me regarding the issues discussed or the research.**
☐ **Finally thank the interviewee for her time and reiterate confidentiality / anonymity**

END

APPENDIX 5.8: SURVEY RESPONSE RATES

Figure A5.8 below details the number of responses to the postal survey. From the 607 surveys distributed 298 were returned with 309 non-responses. Eighty-nine of the respondents opted to change their mind and declined to complete the survey resulting in a response rate of 34%. Non-response can be problematic within survey research as it can reduce the effective sample size and introduce bias (Edwards *et al*., 2002). These issues were not of great concern here as statistical analysis was not the aim of the survey. It is worth reflecting on the issue of response rates however. While steps were taken with the aim of improving the response rate the survey itself was lengthy which could have impacted on willingness to complete the survey and thus reduced the response rate.

A further 32 surveys were excluded. Firstly due to a data error within the mailing list utilised for the study some potential respondents (n=28) had experienced a transient ischaemic attack (TIA) as opposed to a stroke and responses from such individuals were therefore excluded, secondly proxy responses were not to be included and as such all proxy responses (n=4) were excluded from the database. This meant a total of 177 surveys were placed within the study database.

Figure A5.7: Survey Distrubution and Response

Surveys Distributed	607
Non-responses	309
Responses	298
Declined	89
Response rate	34%
Excluded	32
Surveys added to database	177

The data from all respondents, including those who declined to be interviewed, was shared with HIC for secondary analysis; however the full survey sample was not of concern to this thesis. Of 70 survey respondents stated that they would be willing to be interviewed. Prior to beginning the process of purposive sampling the list of 70 prospective interviewees was sent to HIC who screened each interviewee to ensure none had died or been hospitalised in the interim period. None of the prospective interviewees had passed away or been hospitalised.

APPENDIX 6.1: SOCIAL CAPITAL INDICATORS FROM THE POSTAL SURVEY

Table A6.1: SOCIAL CAPITAL INDICATORS: FEMALE INTERVIEWEES

	Spouse	Family Contact	Friendship Contact	Other acquaintances	Reduction in social contact
Victoria	Yes	Regular	Occasional	None	Yes
Grace	No	Occasional	Occasional	Neighbours Club (sports)	No
Kelly	No	Occasional	Occasional	Neighbours Minister	No
Miranda	No	Regular	Regular	Neighbours Former colleagues Club (sport) Club (social)	No
Caitlin	Yes	Regular	Regular	Rehab 'friends' Current colleagues	Yes
Lauren	Yes	Occasional	None	Healthcare Pros Club (stroke)	No
Iona	Yes	Regular	Regular	Neighbours Club (sport) Club (arts) Healthcare Pros	Yes
Jessica	Yes	Regular	Occasional	Neighbours Club (arts)	Yes
Yvonne	No	Regular	None	Formal Carers	Yes
Eloise	Yes	Regular	Occasional	GP	Yes
Shirley	No	Occasional	None	A neighbour Healthcare Pros Consultant Club (stroke)	Yes
Tabitha	Yes	Occasional	Regular	Club (art) Former colleagues	Yes
Martha	Yes	Regular	Occasional	A former colleague	Yes

Table A6.2: SOCIAL CAPITAL INDICATORS: MALE INTERVIEWEES

	Spouse	Family Contact	Friendship Contact	Other acquaintances	Reduction in social contact
Frank	Yes	Regular	Regular	Neighbours Former colleagues Club (stroke)	No
Max	Yes	Regular	Regular	Former colleagues Club (sports) Fellow Pub regulars	No
Chris	Yes	Regular	Occasional	Neighbours Club (sports)	Yes
Paul	Yes	Occasional	Regular	Neighbours Club (arts)	No
Craig	Yes	Occasional	Occasional	Neighbours Former colleagues	Yes
Oliver	Yes	Regular	Occasional	Neighbours	No
Albert	Yes	Regular	Occasional	Neighbours Club (sports)	No
Greg	Yes	Occasional	Regular	Neighbours Former colleagues Club (sports)	Yes
Tam	No	Occasional	Regular	Neighbours Former colleagues	No
Fraser	No	Regular	Occasional	Former colleagues	No
Callum	Yes	Occasional	Occasional	Neighbours Former and current colleagues	No
Kyle	Yes	Occasional	Regular	Neighbours Club (sports)	No
Niall	Yes	Regular	Regular	Neighbours Club (sports)	No

APPENDIX 6.2: INTERVIEWEE RESPONSES TO THE SOCIAL RELATIONSHIPS SUB-SCALE (BOSS)

	Because of your stroke, how difficult is it for you to…					
	Enjoy leisure activities with friends or relatives?					
Interviewee	**Not at all**	**A little**	**Moderately**	**Very**	**Cannot Do**	**N/A**
Victoria				√		
Grace	√					
Kelly	√					
Miranda	√					
Caitlin			√			
Lauren			√			
Iona		√				
Jessica				√		
Yvonne						√
Eloise			√			
Shirley		√				
Tabitha			√			
Martha			√			
Frank			√			
Max		√				
Chris				√		
Paul			√			
Craig		√				
Oliver	√					
Albert	√					
Greg			√			
Tam		√				
Fraser		√				
Callum		√				
Kyle		√				
Niall		√				
Totals	**5**	**9**	**8**	**3**	**0**	**1**
	Total of responses indicating at least some impact					**20**

	Because of your stroke, how difficult is it for you to…					
	Keep old friendships going?					
Interviewee	Not at all	A little	Moderately	Very	Cannot Do	N/A
Victoria				√		
Grace	√					
Kelly	√					
Miranda	√					
Caitlin		√				
Lauren		√				
Iona	√					
Jessica			√			
Yvonne						√
Eloise			√			
Shirley	√					
Tabitha			√			
Martha		√				
Frank		√				
Max	√					
Chris				√		
Paul		√				
Craig	√					
Oliver	√					
Albert	√					
Greg			√			
Tam		√				
Fraser		√				
Callum		√				
Kyle	√					
Niall		√				
Totals	**10**	**9**	**4**	**2**	**0**	**1**
	Total of responses indicating at least some impact					**15**

	Because of your stroke, how difficult is it for you to…					
	Maintain your role as a friend or family member?					
Interviewee	**Not at all**	**A little**	**Moderately**	**Very**	**Cannot Do**	**N/A**
Victoria			√			
Grace	√					
Kelly	√					
Miranda	√					
Caitlin			√			
Lauren		√				
Iona	√					
Jessica				√		
Yvonne	√					
Eloise			√			
Shirley	√					
Tabitha			√			
Martha			√			
Frank	√					
Max	√					
Chris				√		
Paul			√			
Craig	√					
Oliver	√					
Albert	√					
Greg			√			
Tam	√					
Fraser	√					
Callum		√				
Kyle		√				
Niall		√				
Totals	**13**	**4**	**7**	**2**	**0**	**0**
	Total of responses indicating at least some impact					**13**

	Because of your stroke, how difficult is it for you to…					
	Interact with people you're meeting for the first time?					
Interviewee	**Not at all**	**A little**	**Moderately**	**Very**	**Cannot Do**	**N/A**
Victoria				√		
Grace	√					
Kelly	√					
Miranda	√					
Caitlin				√		
Lauren			√			
Iona		√				
Jessica			√			
Yvonne						√
Eloise				√		
Shirley	√					
Tabitha			√			
Martha			√			
Frank			√			
Max	√					
Chris				√		
Paul		√				
Craig	√					
Oliver	√					
Albert	√					
Greg			√			
Tam		√				
Fraser		√				
Callum		√				
Kyle	√					
Niall		√				
Totals	**9**	**6**	**6**	**4**	**0**	**1**
	Total of responses indicating at least some impact					**16**

	Because of your stroke, how difficult is it for you to…					
	Interact with friends and family members?					
Interviewee	**Not at all**	**A little**	**Moderately**	**Very**	**Cannot Do**	**N/A**
Victoria			√			
Grace	√					
Kelly	√					
Miranda	√					
Caitlin			√			
Lauren		√				
Iona		√				
Jessica			√			
Yvonne		√				
Eloise			√			
Shirley	√					
Tabitha			√			
Martha			√			
Frank			√			
Max	√					
Chris			√			
Paul		√				
Craig	√					
Oliver	√					
Albert	√					
Greg			√			
Tam		√				
Fraser		√				
Callum		√				
Kyle	√					
Niall		√				
Totals	**9**	**8**	**9**	**0**	**0**	**0**
	Total of responses indicating at least some impact					**17**

	How often do difficulties in social situations or relationships cause you to feel anxious, unhappy, or frustrated?					
Interviewee	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**	**N/A**
Victoria				√		
Grace	√					
Kelly	√					
Miranda	√					
Caitlin				√		
Lauren		√				
Iona		√				
Jessica			√			
Yvonne	√					
Eloise			√			
Shirley	√					
Tabitha			√			
Martha			√			
Frank			√			
Max	√					
Chris				√		
Paul		√				
Craig	√					
Oliver	√					
Albert	√					
Greg			√			
Tam		√				
Fraser		√				
Callum			√			
Kyle	√					
Niall		√				
Totals	**10**	**6**	**7**	**3**	**0**	**0**
	Total of responses indicating at least some impact					**15**

	How much do difficulties in social situations or relationships cause you to feel dissatisfied with yourself or your life?					
Interviewee	**Not at all**	**A little**	**Some**	**A lot**	**Completely**	**N/A**
Victoria				√		
Grace	√					
Kelly	√					
Miranda	√					
Caitlin				√		
Lauren		√				
Iona		√				
Jessica			√			
Yvonne	√					
Eloise			√			
Shirley	√					
Tabitha			√			
Martha			√			
Frank			√			
Max	√					
Chris				√		
Paul		√				
Craig	√					
Oliver	√					
Albert	√					
Greg			√			
Tam		√				
Fraser		√				
Callum			√			
Kyle	√					
Niall	√					
Totals	**11**	**5**	**7**	**3**	**0**	**0**
	Total of responses indicating at least some impact					**15**

	How much do difficulties in social situations or relationships prevent you from doing the things in life that are important to you?					
Interviewee	Not at all	A little	Some	A lot	Completely	N/A
Victoria				√		
Grace	√					
Kelly	√					
Miranda	√					
Caitlin			√			
Lauren		√				
Iona		√				
Jessica			√			
Yvonne	√					
Eloise			√			
Shirley		√				
Tabitha			√			
Martha			√			
Frank			√			
Max	√					
Chris			√			
Paul		√				
Craig	√					
Oliver	√					
Albert	√					
Greg			√			
Tam		√				
Fraser		√				
Callum			√			
Kyle	√					
Niall	√					
Totals	**10**	**6**	**9**	**1**	**0**	**0**
	Total of responses indicating at least some impact					**16**

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